



**Evaluation of Patient Satisfaction and  
Experience of Care for Medicare Beneficiaries  
with End-Stage Renal Disease (ESRD): Impact of  
the ESRD Prospective Payment System (PPS)  
and ESRD Quality Incentive Program (QIP)  
Final Report**

**July, 2014**

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## **EXECUTIVE SUMMARY**

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This report describes research that Acumen, along with our partner, Westat, conducted for the Centers for Medicare & Medicaid Services (CMS). The project assessed the impact of a new payment system and new quality incentives on Medicare beneficiaries with end-stage renal disease (ESRD). Under the ESRD Prospective Payment System (PPS), implemented in 2011, a service provider or a renal dialysis facility receives a bundled payment for a patient's renal dialysis services. The ESRD Quality Incentive Program (QIP), implemented in 2012, was designed to ensure that service providers and renal dialysis facilities would meet or exceed performance and quality targets. Both the PPS and QIP were established in accord with the Medicare Improvements for Patients and Providers Act of 2008. The research that Acumen and Westat conducted was designed to assess beneficiary experiences and satisfaction, including unintended consequences, following ESRD PPS/QIP implementation.

### ***Methodology***

The project included two major research components, a telephone survey of ESRD beneficiaries (Beneficiary Survey) and a series of in-depth interviews with stakeholders in the renal community (Stakeholder Interviews).

Acumen and Westat designed, administered, and analyzed the results from the Beneficiary Survey, which targeted Medicare beneficiaries with ESRD who were affected by PPS/QIP implementation. Sampling was performed in September 2013 based on Medicare claims and enrollment data as well as data from Dialysis Facility Compare. The stratified sample oversampled subpopulations of interest to ensure that adequate sample sizes would be available for analysis of potentially vulnerable populations. The survey asked beneficiaries about their care experience in the past 3 months, and was administered to 2,535 beneficiaries by telephone from October 2013 through January 2014.

The Stakeholder Interviews were conducted with front-line dialysis staff, nephrologists, and other ESRD stakeholders, such as executives in dialysis organizations or professional organizations. Participants were recruited and interviewed from September through December 2013. Interviews were conducted by telephone for an average administration time of 60 minutes.

### ***Results of Beneficiary Survey***

Results from the Beneficiary Survey suggest that patient experience of care after the implementation of the PPS and QIP is generally positive. Ratings of kidney care doctors and care teams were generally high, with small differences in experiences and outcomes across beneficiary subpopulations.

As a result of many factors, including the PPS and QIP, an increasing number of beneficiaries are receiving dialysis at home. This population, however, still represents a small

fraction of ESRD beneficiaries (less than 10 percent). Interestingly, not all groups of beneficiaries are adopting this modality equally. Beneficiaries with at least some college education reported at-home dialysis rates over twice that of beneficiaries with a high school education or less. Over 10 percent of White non-Hispanic beneficiaries dialyze at home, while about six percent of non-White or Hispanic beneficiaries reported at-home treatment. Beneficiaries receiving care from urban facilities and those aged 20 to 64 were also more likely to dialyze at home.

As a measure of quality of care, the Beneficiary Survey assessed patient experience—specifically communication with kidney doctors and the kidney care team. Upwards of 80 percent of all beneficiaries reported positively on most communication measures. Perhaps as a result of the care and appointment structure, beneficiaries dialyzing at home reported significantly more positive communication with health care professionals. For example, almost 98 percent of this group reported that doctors usually or always treated them with respect, compared with about 85 percent of facility-based beneficiaries. Beneficiaries with college education and those who reported their health to be “Good” or better also reported more positive communications, including greater levels of shared decision-making about prescription drugs.

Because patient self-care is essential for kidney disease patients, education plays a critical role in dialysis care. The Beneficiary Survey asked about support for setting health goals and receiving education about transplant, dialysis modality, and self-care. More than 80 percent of beneficiaries reported that health care professionals helped them set health goals; among goal setters, more than 90 percent were offered help to reach those goals. Across most measures of education, beneficiaries receiving home dialysis, those in “Good” or better health, and those under age 65 reported receiving more kidney care education.

Measures that assess quality of life are important in assessing the impact of any program or system change on beneficiaries. Beneficiaries were asked to report how often they were bothered by fluid and diet restrictions, and how often they felt downhearted or blue. Those receiving home dialysis and those in good health reported higher scores on quality of life measures than their counterparts. Unsurprisingly, beneficiaries with self-reported physical health status of “Fair” or worse reported depressive symptoms and greater burden from fluid and dietary restrictions, with differences ranging from 12.7 to 18.4 percentage points higher than beneficiaries with self-reported physical health status of “Good” or better.

## ***Results of Stakeholder Interviews***

The 30 stakeholder interviews yielded a wide range of views about the consequences of the PPS and QIP. Although there was not consensus across all respondents, a few key themes emerged, including the impact of cost-cutting efforts, the importance of patient education, changes in dialysis delivery, and changes to meet reporting requirements. Efforts to cut costs in some dialysis facilities were reported to have resulted in shortened facility hours and less patient access to some staff, including social workers and dietitians. These changes were clearly noted as barriers to positive patient experience and quality of life. Stakeholders also noted that lab tests that are needed to support patient care but that are not directly related to dialysis services were no longer being performed (due to cost), causing patients to have to seek care across a greater number of health care sources.

Not all consequences noted were negative, however. Many stakeholders cited an increased emphasis on patient education to ensure a smooth start to dialysis for new patients, and ongoing education for existing patients. Although education initiatives may have stemmed from the need to manage costs, patients benefited from this change. Other new and focused initiatives included greater discussion with patients about types of treatment, such as home dialysis. Again, while home dialysis is less costly for facilities, many stakeholders agreed that for the right patients, home dialysis offered improved quality of life.

A final set of consequences stemmed from the new reporting requirements – both the clinical measures as well as the reporting itself. Some stakeholders reported that, to meet QIP standards, patients were encouraged to undergo longer dialysis treatments. It was unclear to some stakeholders whether the longer treatments resulted in a measurable health improvement for patients, or just better clinical outcome metrics. Regarding the reporting process itself, a few stakeholders noted the burden associated with the additional reporting requirements, and suggested that these required anything from a systems overhaul to more staff time to accomplish the reporting.

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# 1 INTRODUCTION

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In 2011 the Centers for Medicare & Medicaid Services (CMS) contracted with Acumen, and subcontractor Westat, to conduct the Evaluation of Patient Satisfaction and Experience of Care for Medicare Beneficiaries with End-Stage Renal Disease (ESRD): Impact of the ESRD Prospective Payment System (PPS) and ESRD Quality Incentive Program (QIP). The ESRD PPS, implemented in January 2011, is a result of the Medicare Improvements for Patients and Providers Act of 2008 (MIPPA), which directed the Secretary of the Department of Health and Human Services to implement a payment system in which a service provider or a renal dialysis facility receives a single bundled payment for renal dialysis services, replacing the previous case-mix-adjusted composite payment system. MIPPA also stipulated the development of quality incentives for the ESRD program, with the goal of ensuring that service providers and renal dialysis facilities would meet or exceed established performance and quality targets. The QIP was implemented in January 2012.

Following implementation of the ESRD PPS/QIP in 2011 and 2012, CMS contracted with Acumen and Westat to assess the impact of the payment system and quality incentives on ESRD beneficiary experiences, satisfaction, and health outcomes. The project included the design and implementation of a qualitative and quantitative evaluation of the impact of the ESRD PPS/QIP on beneficiary satisfaction and experience of care, including unintended consequences. The project had two major components: a telephone survey of ESRD beneficiaries to assess their experience in receiving care after implementation of the ESRD PPS/QIP (the Beneficiary Survey), and 30 in-depth interviews with stakeholders in the renal community (Stakeholder Interviews).

The purpose of the Beneficiary Survey was to measure beneficiary satisfaction and experience of care after ESRD PPS/QIP implementation. The PPS and the QIP represented significant changes in billing, reimbursements, and quality reporting for Medicare beneficiaries with ESRD. In light of the notable changes resulting from the PPS and QIP, CMS wanted to ensure that there were no unintended consequences negatively affecting quality of care or outcomes for patients. Drawing on existing ESRD, patient experience, and satisfaction measures, Westat designed a survey to assess ESRD patient experience of care and satisfaction. Beneficiary Survey data will be used in conjunction with data from other components of the study to describe the impact of the ESRD PPS/QIP on patient satisfaction and experience of care.

The purpose of the Stakeholder Interviews was to systematically collect information about the issues facing beneficiaries as a result of the payment system and quality incentives. A secondary objective was to provide information to CMS regarding any possible missing domains or topics in the current In-Center Hemodialysis Consumer Assessment of Healthcare Providers and Systems (ICH-CAHPS) survey.

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## 2 METHODOLOGY AND APPROACH

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In this section, we describe the methodology used to collect data for the Evaluation of Patient Satisfaction and Experience of Care for Medicare Beneficiaries with End-Stage Renal Disease: Impact of the ESRD Prospective Payment System and ESRD Quality Incentive Program. Methods are described for the Beneficiary Survey and the Stakeholder Interviews.

### 2.1 Beneficiary Survey

As part of the Evaluation of Patient Satisfaction and Experience of Care for Medicare Beneficiaries with ESRD: Impact of the ESRD Prospective Payment System and ESRD Quality Incentive Program project, Acumen's partner, Westat designed, administered, and analyzed the results from the Beneficiary Survey.

The remainder of this section describes the Beneficiary Survey sampling, survey design and administration, and sample weighting.

#### 2.1.1 Sampling

The sampling frame was constructed in September 2013 using the most current Medicare claims and enrollment data as well as facility characteristics from Dialysis Facility Compare.

Since the main objective of the Beneficiary Survey was to measure the impact of PPS/QIP implementation, the target population excluded those Medicare beneficiaries with ESRD who were not affected by the PPS/QIP implementation, specifically:

- Transplant patients
- Inpatient hemodialysis patients
- Hospice care patients
- Patients receiving home hemodialysis or peritoneal dialysis under "Method 2" (getting equipment and supplies from a durable medical equipment provider)
- Pediatric patients
- Patients who enrolled after January 1, 2011, when the PPS/QIP was already implemented.

Characteristics of the target population are shown in Table 2-1.

**Table 2.1: Characteristics of the Target Population for the Beneficiary Survey**

Variable	Category	Percent Distribution
Dialysis treatment	In-center treatment hemodialysis	91.2
	Home/peritoneal treatment	8.4
	More than one type of treatment	0.4
Race/ethnicity	White, non-Hispanic	44.5
	African American, non-Hispanic	40.8
	Hispanic, any race	7.1
	Other (includes Asian, Native American)	7.2
	Unknown	0.4
Gender	Male	53.9
	Female	46.1
Age	20-44	14.9
	45-64	42.6
	65-74	23.3
	74+	19.2
Beneficiary residence location	Urban	83.8
	Non-urban	16.2
Facility ownership	Profit	88.9
	Non-profit	10.6
	Unknown	0.5
Facility type (patient distribution)	Large dialysis organization (LDO)	72.7
	Small dialysis organization (SDO)	15.5
	Hospital-based	1.7
	Independent	10.0

## Stratification

The Beneficiary Survey used a stratified sample design to oversample important subpopulations of interest and therefore ensure that adequate sample sizes would be available for analysis. Westat used the following characteristics for stratification:

- Treatment modality (hemodialysis or peritoneal dialysis)
- Treatment location (in-facility or home)
- Facility type (large dialysis organization [LDO], small dialysis organization [SDO], hospital-based facility, or independent facility)
- Further subgroups of analytic interest were identified. These included:
  - Demographic characteristics (race/ethnicity, age, and gender)
  - Geographic location (urban/rural)
  - Characteristics of dialysis facility (ownership, size)

The goal of identifying subgroups was to ensure an adequate sample size for vulnerable populations (the elderly, minority race/ethnicity, and beneficiaries in rural areas) so that meaningful analysis of these population groups would be feasible. Based on the representation of these groups within the sample frame, it was determined that oversampling of smaller minority race/ethnicity

subgroups within existing strata would be required, with a probability two times larger than the probability for other beneficiaries within each stratum. This strategy yielded sufficient representation of all minority populations to permit analysis and prevented the creation of fragmented strata.

## Sample Allocation and Selection

The Beneficiary Survey had a target of 2,500 completed surveys, which was allocated to the strata to ensure at least 300 respondents for each analysis subgroup. Further, our goal was to complete 2,000 surveys for the in-center stratum and 500 surveys for the home/peritoneal stratum. The in-center stratum of 2,000 was further allocated to LDOs (1,000 surveys), SDOs (600 surveys), and hospital-based/independent facilities (400 surveys). This allocation introduced moderate variability in the sampling probabilities between the substrata, while allocating a sufficiently large sample size to each substratum.

Using the allocation described above, and selecting beneficiaries belonging to certain minority race/ethnicity subgroups with a probability two times larger than the probability for other beneficiaries, we projected the number of completes by race/ethnicity group as shown in Table 2.2.

**Table 2.2: Expected Completes by Strata Race/Ethnicity Subgroups**

Race/Ethnicity Group	Population Percent	Probability Ratio	LDO	SDO	Hospital/Indep	Home	Total
White, non-Hispanic	44.5	1	389	234	156	195	973
African American, non-Hispanic	40.8	1	357	214	143	179	894
Hispanic, any race	7.1	2	124	74	49	62	309
Other, non-Hispanic	7.2	2	126	76	50	63	315
Unknown	0.4	1	4	2	1	2	9
Total	100.0		1,000	600	400	500	2,500

Based on an expected 40 percent response rate, the desired number of completes was inflated by a factor of 2.5 ( $= 1/0.4$ ) to derive the sample sizes for sample selection. Furthermore, reserve samples were drawn to supplement the sample as needed to achieve survey goals. Note that the home/peritoneal stratum was not supplemented with additional sample in reserve sample 2 because the target number of completes was reached with the initial and reserve sample 1. The unconditional sampling probability of the combined sample of 9,550 was derived as if it had been selected at once. This topic is further discussed in the weighting section, and detailed discussion is provided in Appendix A. Table 2.3 presented below shows sample sizes by stratum.

**Table 2.3: Sample Allocation Scheme by Stratum**

Stratum	Target Completes	Initial Sample	Reserve Sample 1	Reserve Sample 2	Total Fielded Sample
LDO	1,000	2,500	1,000	322	3,822
SDO	600	1,500	600	288	2,388
Hospital/Independent	400	1,000	400	190	1,590
Home	500	1,250	500	0	1,750
Total	2,500	6,250	2,500	800	9,550

The sample was selected using the SAS procedure SURVEYSELECT with the probability proportional to size sampling method, and with the measure of size (MOS) equal to two for the beneficiaries belonging to the minority race/ethnicity subgroups (i.e., Hispanic and non-Hispanic other races than White and Black) and equal to one for other beneficiaries.

The sample frame did not include a telephone number, which was required to conduct telephone data collection. Across all 9,550 sampled records, we obtained at least one phone number for 7,805 records through a telephone matching service.

### ***2.1.2 Beneficiary Survey Design and Administration***

The primary purpose of the Beneficiary Survey was to measure the possible impact of the ESRD PPS/QIP on patient satisfaction and experience of care. Given that the one-time survey would follow changes in billing, reimbursements, and reporting, and taking into account the poor and declining health of most ESRD beneficiaries, the survey design team agreed that asking beneficiaries about their current experience in receiving care (in the past 3 months) would yield the most meaningful data.

Westat developed the Beneficiary Survey based on relevant questions, scales, and measures from existing methodologically sound survey instruments, including:

- In-Center Hemodialysis CAHPS survey;
- Kidney Disease Quality of Life (KDQOL) questionnaire;
- Medicare CAHPS;
- Medicare Current Beneficiary Survey; and
- National Health Interview Survey.



## Survey Pre-Testing

In 2012, Westat conducted a round of cognitive testing on the draft Beneficiary Survey. Cognitive testing was designed to capture information about how respondents understood the questions, how they thought about their own experiences and translated those to the question, and how they selected a response category to represent their experiences. Cognitive testing was conducted with nine ESRD Medicare beneficiaries who met the following criteria:

- At least 18 years of age;
- Enrolled in the CMS ESRD program prior to January 1, 2011;
- Never having received a kidney transplant;
- Not currently receiving inpatient hemodialysis; and
- Not receiving home hemodialysis or peritoneal dialysis under “Method II”<sup>1</sup>.

Participants varied in age, gender, race/ethnicity, and type of dialysis received. Additionally, participants represented a mix of those who received care from for-profit or non-profit dialysis centers in rural and urban/suburban locations.

To cover all CMS research questions, the draft Beneficiary Survey contained 103 close-ended questions and 4 open-ended questions. Each question was crosswalked to one of the following research domains:

- Beneficiary access to care, such as treatment modality, prescription drugs, shared decision making, and other medical treatment;
- Beneficiary quality of care, such as patient experience, management of treatment, and self-management/support;
- Beneficiary quality of life and health outcomes;
- Beneficiary out-of-pocket costs; and
- Beneficiary demographics and social support.

After we completed cognitive testing of the Beneficiary Survey, the survey was revised to reduce the length, eliminate questions that underperformed and include considerations for accepting proxy answers to assist beneficiaries in completing the survey. The final Beneficiary Survey contained 50 closed-ended questions and 4 open-ended questions covering the domains listed above. The complete Beneficiary Survey is found in Appendix B.

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<sup>1</sup> Once implementing the ESRD PPS, all Method II beneficiaries became Method I.

## **Interviewer Training**

All interviewers underwent self-paced training, with examinations on the tenets of standardized interviewing, including gaining respondent cooperation. Additionally, interviewers were trained intensively on the Beneficiary Survey. Project-specific training included a review of questions contained in the interview, an overview of key terms and definitions, and sensitivity training regarding ESRD beneficiaries and dialysis treatment. Interviewers were monitored intensively and coached throughout their training.

## **Recruitment**

Potential respondents originated from Medicare claims and enrollment data and/or data from databases, including the Renal Management Information System (REMIS), the Medicare Beneficiary Database (MBD), and the ESRD Network Organizations' Standard Information Management System (SIMS).

Since beneficiary telephone numbers were not available in the sample file, a telephone matching service (LexisNexis Accurint®) provided up to three telephone numbers of ESRD beneficiaries by matching them by first name, last name, address, city, state, and age.

## **Beneficiary Pre-Notification**

Prior to data collection, beneficiaries were mailed a pre-notification letter. The goal of the letter was to introduce the study, emphasize confidentiality, explain respondents' rights, and alert respondents that an interviewer would call them. The letter included a Beneficiary Survey toll-free number and email address that beneficiaries could use to verify the legitimacy of the study, ask questions, or schedule an appointment for an interview. A sample pre-notification letter is presented in Appendix C.

## **Survey Administration**

The Beneficiary Survey was administered by telephone by professional interviewers from Westat's Telephone Research Center. Because ESRD patients are a vulnerable population with many health concerns, the interviewers were specially trained to interact with ESRD beneficiaries and their caregivers.

The Beneficiary Survey was programmed in Westat's computer-assisted telephone interviewing (CATI) system. The CATI system was used to manage all aspects of data collection, displaying question text to be read, implementing all skip patterns and question customization for text fills, prioritizing of case calling, scheduling of call backs, storing data, and tracking of all case call history.

Outreach to beneficiaries, call backs, and re-contacts were managed within Westat's Telephone Research Center. Respondents could call the dedicated Beneficiary Survey toll-free number to ask questions, request immediate call backs, or schedule changes in their interview appointment times and dates.

### **Handling of Special Respondent Cases**

Although most respondents were able to complete the survey without assistance, some respondents required special accommodations. Some beneficiaries were unable to complete the survey because they were too sick to answer the survey or were not able to communicate with the interviewer. In these cases, we accepted a proxy to answer survey items on behalf of the beneficiary. The decision to accept proxies represented a trade-off between response rate and data purity. Through the cognitive testing, we determined that family members and caregivers were able to respond adequately to the survey, and generally did so with input from the sampled ESRD beneficiary.

As needed, a Spanish-language version of the survey was administered by a Spanish bilingual interviewer.

### **Data Cleaning**

Upon completion of data collection, survey data were imported into SAS® software for data manipulation, cleaning, weighting, and analysis. Frequencies and cross-tabulations were used to verify that all skip patterns were correctly implemented and item-specific ranges were applied. All open-ended comments and interviewer notes were reviewed and data updated as needed. Cases where respondents did not complete the survey through the first full section (at least question 21) were excluded from the final analytic file.

### **Survey Administration Statistics**

The Beneficiary Survey was administered from October 2013 through January 2014, with a response rate of 28.9 percent<sup>2</sup>. For quality control, approximately 10 percent of all interviewing time was monitored by a supervisory team who could silently listen in to the call and view the interviewer's desktop. Call yield and results for the 9,550 sampled cases are shown in Table 2.4.

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<sup>2</sup> A non-response/non-coverage bias analysis study was conducted and submitted to CMS in a separate report.

**Table 2.4: Beneficiary Survey Administration Statistics**

Call yield and results	N
Completed Surveys	2,535
Ineligibles*	777
Refusals	1,276
Non-Response	3,364
No telephone numbers	1,598
<b>Total</b>	<b>9,550</b>

\* Ineligibles included those beneficiaries who were deceased, who did not receive dialysis in the past 3 months, or who had a kidney transplant since March 2011, and eligibility unknown cases that were imputed to be ineligible.

### **2.1.3 Weighting**

The ESRD sample data were weighted in multiple steps as shown below:

- Determination of the unconditional sampling probability for the combined sample and the base weight
- Imputation of the frame variables and survey eligibility
- Raking procedure to adjust the base weight to benchmark to the population totals
- Nonresponse adjustment
- Replicate weighting for variance estimation

These steps are described in the sections that follow. More detailed explanations are provided in Appendix A.

### **Determination of the Unconditional Sampling Probability and the Base Weight**

The base weight is defined as the inverse of the sampling probability. For the combined sample of 9,550, the unconditional sampling probability was determined to account for the entire sampling procedure. This unconditional sampling probability (“sampling probability” hereafter) was the basis for the base weight calculation.

The sampling probability within each stratum was established based on the beneficiary’s race/ethnicity. Beneficiaries of Hispanic origin and non-Hispanic “other” races (Asian, Pacific Islander, and American Native) were given probability twice as large as other race/ethnicity groups that include the non-Hispanic White, non-Hispanic Black, and unknown. Derivation of the sampling probability is explained in detail in Appendix A.

Once the sampling probability was derived, the base weight was calculated as the inverse of the probability. Denoting the sampling probability for an arbitrary sampled beneficiary  $u$  by  $P_u$ , the base weight for the beneficiary is algebraically defined by

$$W_u = \frac{1}{P_u}.$$

Table 2.5 provides the sample counts, the sampling probability, and the corresponding base weight by stratum and race/ethnicity group.

**Table 2.5: Sample Size, Unconditional Sampling Probability, and Base Weight by Stratum and Race/Ethnicity**

Stratum	Race/Ethnicity	Original Sample Size	Additional Sample Size	Sampling Probability	Base Weight
1A	0	2700	322	0.04374	22.86
1A	1	2700	322	0.04374	22.86
1A	2	2700	322	0.04374	22.86
1A	3	2700	322	0.08716	11.47
1A	5	2700	322	0.08716	11.47
1B	0	1620	288	0.12591	7.94
1B	1	1620	288	0.12591	7.94
1B	2	1620	288	0.12591	7.94
1B	3	1620	288	0.24793	4.03
1B	5	1620	288	0.24793	4.03
1C	0	1080	190	0.12082	8.28
1C	1	1080	190	0.12082	8.28
1C	2	1080	190	0.12082	8.28
1C	3	1080	190	0.23811	4.20
1C	5	1080	190	0.23811	4.20
2	0	1350	0	0.17505	5.71
2	1	1350	0	0.17505	5.71
2	2	1350	0	0.17505	5.71
2	3	1350	0	0.35011	2.86
2	5	1350	0	0.35011	2.86

As described previously (see section 2.1.1), probability proportional to size sampling was used to oversample two minority race/ethnicity groups (i.e., beneficiaries with Hispanic ethnicity, and non-Hispanic other races). Because of the probability proportional to size sampling method, the weights do not sum to the known population size. Table 2.6 shows the differences between the sums of the base weights and the known population sizes obtained from the sample frame at various aggregation levels. This issue was addressed by using the raking procedure, which is described later in this section.

**Table 2.6: Sums of the Base Weights, Population Sizes, and Their Percent Differences at Various Aggregation Levels**

Stratum	Race/Ethnicity	Aggregation Level <sup>1</sup>	Population Size	Sum of Base Weights	Percent Difference
		0	113,226	114,054.2	0.73
	0	1	456	414.47	-9.11
	1	1	45,928	47,060.63	2.47
	2	1	50,335	50,903.02	1.13
	3	1	8,158	7,091.69	-13.07
	5	1	8,349	8,584.41	2.82
1A		2	77,362	77,601.80	0.31
1B		2	15,966	16,053.35	0.55
1C		2	11,210	11,227.55	0.16
2		2	8,688	9,171.53	5.57
1A	0	3	262	251.51	-4.00
1A	1	3	29,776	30,043.59	0.90
1A	2	3	37,229	37,451.60	0.60
1A	3	3	4,739	4,164.61	-12.12
1A	5	3	5,356	5,690.49	6.25
1B	0	3	79	55.59	-29.63
1B	1	3	6,601	6,774.41	2.63
1B	2	3	6,191	6,218.48	0.44
1B	3	3	1,689	1,568.98	-7.11
1B	5	3	1,406	1,435.88	2.13
1C	0	3	57	33.11	-41.91
1C	1	3	4,837	4,775.69	-1.27
1C	2	3	4,308	4,428.07	2.79
1C	3	3	1,013	923.95	-8.79
1C	5	3	995	1,066.74	7.21
2	0	3	58	74.26	28.03
2	1	3	4,714	5,466.93	15.97
2	2	3	2607	2804.87	7.59
2	3	3	717	434.16	-39.45
2	5	3	592	391.31	-33.90

<sup>1</sup> 0: Population; 1: Race/Ethnicity; 2: Stratum; 3: Cross-Classification of Stratum and Race/Ethnicity

## Imputation of Frame Variables and Survey Eligibility

Several variables from the sampling frame were used in the weighting procedures. Some frame variables included missing or unknown values. To use the frame variables in weighting, missing and unknown values were imputed using Westat's proprietary imputation software, AutoImpute, a SAS® program based on the generalized linear model. Imputation was conducted in several steps to obtain the best results based on the predictive power of the non-missing data from the 103 frame variables.

Altogether, 78 variables were imputed with mostly a small imputation rate. Only three variables had an imputation rate higher than 1 percent: PROFIT\_NON (whether the dialysis facility is for-profit or non-profit) with 1.3%, AVG\_HEMO (average hemoglobin level) with 13.1%, and Eligibility (whether the sampled individual is eligible for the Beneficiary Survey) with 56.6%. While the Eligibility status is not a frame variable, it was imputed to aid weighting.

It is worth noting that eligibility was unknown for 56.6 percent of sampled beneficiaries; eligibility status was imputed for these beneficiaries. If imputation had not been used, we would have estimated the number of eligible cases among the unknown cases (5,408) using the eligibility rate among the known cases (4,142), which was 92.01 percent. Imputation improved over this simple method, resulting in an improved eligibility rate of 91.86 percent.

Frame variables that were imputed and their imputation rates are presented in Appendix A.

## Raking Procedure

As previously described, the calculated base weights did not sum to the known population sizes at various aggregation levels. We used the raking procedure to further refine the weights. The variables that define the subpopulations of interest are:

- Dialysis and facility type stratum (hemodialysis, LDO; hemodialysis, SDO; hemodialysis, independent or hospital-based; peritoneal or home dialysis)
- Race/ethnicity (non-Hispanic White; non-Hispanic Black; non-Hispanic Asian/Native American/other; and Hispanic, all races)
- Gender (male or female)
- Age group (18-44; 45-64; 65-74; 75+)
- Location (rural or urban)
- Ownership (for-profit or non-profit)

We performed two-dimensional raking, where one dimension was defined by cross-classes of the first three variables (stratum, race/ethnicity, and gender), and the other dimension was defined by cross-classes of the last three variables (age, location, and facility ownership).

The original and adjusted counts (control totals) are presented in Tables A-4 and A-5 in Appendix A.

The raking procedure adjusted the base weights of the combined sample of 9,550 so that the adjusted weights summed to the adjusted count in each of the cross-classes. This also guarantees that the sum of adjusted weights at any higher aggregation is equal to the adjusted count at that aggregation.

### **Nonresponse Weighting Adjustment**

Since the unweighted nonresponse rate was 71 percent (the weighted is 70 percent), targeted nonresponse adjustment was required. We used the propensity score method for nonresponse adjustment to fully exploit the rich auxiliary information in the frame. Another frequently used approach is using weighting cells created by cross-classes of categorical predictor variables for nonresponse propensity. We first tried the cross-class method using the 10 most significant predictors. This approach did not perform as well as the propensity score method that used many more auxiliary variables in the frame to fit the logistic regression model with the response status as the dependent variable.

To develop the logistic regression model, we first ran the model with all feasible frame variables (103) as predictors using the SAS PROC LOGISTIC with the stepwise option. We also included the raking ratio adjusted weight as a predictor variable. The most significant variables were identified by the forward stepwise option with  $\text{slentry} = 0.3$  and  $\text{slstay} = 0.35$  for a variable to enter and stay in the model. From the run, we identified 42 most significant main effect terms; the list of these variables is shown in Appendix A, Table A-6.

The next step was to identify significant (two-way) interaction terms. All possible 861 interaction terms were included in the model along with 42 main effect terms, and the run provided a list of 903 terms with the p-value for the Chi-square test statistic of the significance of the regression coefficients. To reduce the number of terms, we used 0.2 as the cutoff. The final model included 244 terms with a  $p\text{-value} \leq 0.2$ . The terms that remained in the final model are shown in Table A-7 in Appendix A.

After the model was finalized, the response propensity was predicted by the final model for each eligible unit in the sample ( $N = 8,773$ ). Ten equal-sized weighting cells were then created with similar predicted response propensities.



## **Replicate Weighting for Variance Estimation**

We chose the jackknife variance estimation method for the Beneficiary Survey. Compared with the popular Taylor linearization method, the jackknife method has the advantage of more easily capturing various weight adjustments in variance estimation. The jackknife method is a replication method and requires setting up jackknife replicates and calculating replicate weights.

To create the jackknife replicates appropriate for the stratified design used for the Beneficiary Survey, we defined variance strata and units. Variance strata were the same as the design strata, but the variance units were formed by the random group method (Wolter, 2007). The random group method forms more or less equal-sized groups (clusters) of sample units randomly within each variance stratum.

To ensure adequate degrees of freedom for each for the four Beneficiary Survey strata (domains) for separate domain analysis, we created 30 replicates in each stratum, and 30 variance units in each stratum. The total number of replicates was 120 for the sample.

During the base weighting, the replicate base weights were calculated according to the method appropriate for the jackknife variance estimation method. These replicate base weights were passed through the raking adjustment and nonresponse adjustment process so that the adjustments applied to the base weights were applied to the replicate base weights. In this way, the weight adjustments were captured in the variance estimation. For more detailed discussion of the replicate weighting, see Appendix A.

## **2.2 Stakeholder Interview Protocol and Administration**

This section describes the development of the Stakeholder Interview protocol, recruitment of stakeholders, and the interview process.

### ***2.2.1 Criteria for key stakeholder selection***

Stakeholder Interview respondents included dialysis center managers, nephrologists, care managers, nurses, social workers, dietitians, and nephrology technicians. Great care was taken to achieve a reasonable distribution across these different types of care providers. This mix of stakeholders was prescribed by CMS for the Stakeholder Interviews to capture the perspectives of front-line staff and those who support the ESRD community, to supplement the perspectives of patients captured by the Beneficiary Survey.

### **2.2.2 Identification of Appropriate Respondents and Recruitment Method**

Recruitment of participants for the Stakeholder Interviews was conducted from September 17 through November 20, 2013, with interviews scheduled from September 26 to December 5, 2013. Potential respondents corresponded with recruitment staff via phone and a dedicated project mailbox (ESRDSurvey@westat.com).

Recruitment for the Stakeholder Interviews required a multipronged approach that leveraged lists of known stakeholders in the renal community, contacts with ESRD networks, and recommendations from other interviewees. Although we were able to easily recruit practicing nephrologists, it was more challenging to recruit front-line, non-physician dialysis staff, a task that required considerably more effort and multiple contacts with ESRD networks. A Westat recruiter initially sent emails to schedule the interviews using an email script. Follow-up phone calls were made to potential interviewees who did not respond by email.

In cooperation with Dr. Jay Wish, Westat created a list of potential respondents. In addition, CMS provided Westat a list of physicians who served on the ESRD Quality Measure Development and Maintenance Clinical Technical Expert Panel. These individuals were contacted, and those amenable were interviewed. At the conclusion of each interview, Westat requested that the respondent recommend others who would be appropriate to discuss the ESRD PPS/QIP. This technique is commonly called a “snowball” sample because the recommendations of other participants rapidly increase the number in the sample. Westat invited these recommended stakeholders to participate. Westat also reached out to the directors of all 18 ESRD Network Organizations for potential front-line stakeholder contacts. Westat recruitment staff scheduled interviews with amenable respondents.

During recruitment, Westat tabulated the categories of participants to more precisely track how the cells for each category were allocated to ensure representation among stakeholders and care providers. The 30 in-depth interviews were conducted with knowledgeable respondents in the renal community, distributed across a CMS-directed mix of provider and stakeholder types considered to be optimal for the broader qualitative task of the Stakeholder Interviews. Of the 30 respondents, 19 were front-line dialysis (non-physician) health care providers, such as nurses, social workers, care managers, and dieticians. Four respondents were practicing nephrologists who provide direct patient care. Finally, seven respondents were other ESRD stakeholders, such as executives in dialysis organizations or professional organizations. Table 2.7 presents the respondents by stakeholder type, staff position, facility ownership, and geographic region.

**Table 2.7: Stakeholder Respondents by Type and Associated Characteristics**

Stakeholder Type	Staff Position	Ownership	Region
Front-Line Dialysis Staff	Social Worker (6) Dietician (7) Nurse (2) Care Manager (4)	Non-Profit (5) For-Profit (14)	East North Central (2) East South Central (1) Mid Atlantic (2) Mountain (6) New England (3) Pacific (3) West South Central (2)
Practicing Nephrologists	Nephrologists (4)	Non-Profit (3) For-Profit (1)	East North Central (1) New England (1) Pacific (1) West South Central (1)
Other Stakeholders	Corporate Level Dialysis Organization, Executive Leadership (3) Founder and Formal Medical Director of a Research Organization (1) President of a Workforce Organization (1) Chief Operating Officer of a Dialysis Administrative Organization (1) Dialysis Organization Consultant/Retired Nephrologist (1)	Non-Profit (3) For-Profit (4)	Mid Atlantic (1) New England (1) Pacific (3) South Atlantic (2)

### **2.2.3 Interview Protocol and Administration**

Westat developed the Stakeholder Interview protocol based on the objectives and themes of interest outlined by CMS. The ICH-CAHPS section of the interview protocol was crafted to solicit feedback on all of the existing domains, or content areas, as well as content areas that were not included in the ICH-CAHPS but that were considered important areas of ESRD patient experience. To provide context for their responses, stakeholders were asked a series of initial questions about their place of work, their geographic location, their job title and responsibilities, whether they worked for a for-profit or non-profit organization, and whether they worked for a high-, medium-, or low-volume dialysis center.

The Stakeholder Interview protocol underwent numerous rounds of review and revision before being administered. After the interviews started, the protocol was further revised to streamline discussion and maintain an average administration time of 60 minutes. The protocol was reduced by approximately 20 percent to meet the target of a 60-minute interview.

The interview protocol (Appendix D) consisted of scripted text that the interviewer used to introduce each topic. The interviewer always asked the question in the protocol and followed up with both scripted and unscripted probes, depending on the participant's response. The scripted probes focused on getting the respondent to discuss the various topics. The unscripted probes focused on bringing clarity or detail to the participant's responses. All probing was done in a neutral, non-biasing way.

The interview covered the following domains and topics:

- Respondent's understanding of and experience with ESRD PPS/QIP
- Effects and implications of the ESRD PPS/QIP changes
- Cost of care
- Drugs and biologicals
- Laboratory tests
- Supplies, devices, and durable medical equipment
- Implementation issues
- Quality of care measures and health outcomes
- Beneficiary choice and education
- Patient experience of care
- ICH-CAHPS Survey

All interviews were conducted by telephone at a mutually agreed-upon time. Some respondents chose to be interviewed outside of standard business hours. Interviews ranged from 35 minutes to 90 minutes in length, with most running approximately 60 minutes. Participants were read an introduction that described the study and were provided with the information required for appropriate consent. All interviews were audio-recorded to support note-taking and analysis.

## 3 RESULTS

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The following section presents results from the Beneficiary Survey and the Stakeholder Interviews for each of the study domains. The Beneficiary Survey results are quantitative and presented as univariate and bivariate analysis tables. The Stakeholder Interview results are qualitative and presented as themes with supporting quotes and content drawn directly from interviews.

### 3.1 Beneficiary Survey

The Beneficiary Survey was designed to measure beneficiary experiences with their ESRD care, capturing a “snapshot” in time after the implementation of the PPS and QIP.

In the discussion below, we describe the results from the Beneficiary Survey and present significant results of comparisons across beneficiary and ESRD facility attributes. Beneficiary experiences and outcomes were generally positive; ratings of physicians and care teams were generally high, and differences across beneficiary subpopulations were mostly small and statistically insignificant.

The following survey topics are described below:

- Respondent demographics
- Access to care
- Quality of care
- Beneficiary education
- Health status and outcomes
- Quality of life
- Out-of-pocket costs

With the exception of the demographic characteristics of survey respondents, all data presented are based on weighted data that have been adjusted for nonresponse and have been post-stratified to control totals for the ESRD population in the United States, based on CMS data. Some results may not sum to 100 percent due to rounding.

Statistical testing involved the calculation of Rao-Scott chi-square statistics, which account for design correction to determine whether relationships existed between dichotomous variables. Statistical tests were deemed significant where  $p \leq 0.05$ .<sup>3</sup>

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<sup>3</sup> We also explored whether beneficiary characteristics were predictive of several dichotomous outcomes using weighted logistic regression. We did not report the results of these regressions, however, because the results of some of these analyses resulted in unstable parameter estimates and/or poor model fit.

### 3.1.1 Respondent Demographics

The following section presents a description of the demographics of respondents to the Beneficiary Survey. Demographic characteristics are presented as unweighted data and reflect the stratification and over-sampling conducted to reach the populations of interest. Respondent demographics from the Beneficiary Survey are displayed in Tables 3.1 to 3.4.

#### Respondent Survey Demographics

**Table 3.1: Respondent Race**

Race	Unweighted Results	
	N	Percent Respondents
Non-White or Hispanic <sup>4</sup>	1530	63.3
White, non-Hispanic	888	36.7
TOTAL	2418	100.0
Refused/Don't know	117	

**Table 3.2: Respondent Education**

Education	Unweighted Results	
	N	Percent Respondents
High school or less	1515	62.0
Some college or more	929	38.0
TOTAL	2444	100.0
Refused/Don't know	91	

**Table 3.3: Respondent Marital Status**

Marital status	Unweighted Results	
	N	Percent Respondents
Married	1112	45.3
Living with a partner in a marriage-like relationship	64	2.6
Widowed	360	14.7
Divorced	359	14.6
Separated	123	5.0
Never married	436	17.8
TOTAL	2454	100.0
Refused/Don't know	81	

**Table 3.4: Respondent Income Level per Dependent**

Income	Unweighted Results	
	N	Percent Respondents
Less than \$10,000 per dependent	1130	57.9
\$10,001 or more per dependent	822	42.1
TOTAL	1960	100.0
Refused/Don't know	583	

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<sup>4</sup> Non-white includes Alaska Native, American Indian, Asian, Black or African American, Hispanic or Latino, and Native Hawaiian or other Pacific Islander.

### 3.1.2 Access to Care

#### ***Highlights***

- Over 90 percent of ESRD beneficiaries reported receiving their dialysis in a dialysis center.
- The majority of ESRD beneficiaries reported receiving hemodialysis (93.7 percent), while only 6.3 percent of beneficiaries reported receiving peritoneal dialysis.
- Overall, ESRD beneficiaries who were younger, White, non-Hispanic, not eligible for Medicaid, college educated, or receiving dialysis in an urban environment had significantly higher rates of at-home dialysis than their counterparts.
- Among beneficiaries receiving hemodialysis, men (76.2 percent) reported significantly higher rates of using a fistula than women (62.9 percent).

This section describes how ESRD beneficiaries reported their access to dialysis care. Data presented in this section are based on self-report of beneficiaries. Tables 3.5 through 3.13 summarize how beneficiaries reported their treatment modality, length of time receiving care in that manner, total treatment time, vascular access type, and perceived kidney transplant eligibility.

#### **Dialysis Modality**

Several dialysis treatment modalities are available to ESRD patients. The overwhelming majority of beneficiaries reported receiving their dialysis in a dialysis center (90.4 percent), with smaller percentages dialyzing at home (7.6 percent) or in a hospital setting<sup>5</sup> (2 percent) (Table 3.5).

**Table 3.5: Dialysis Treatment Location**

Location	Percent Beneficiaries
In-center	90.4
At-home	7.6
Hospital	2.0
TOTAL	100.0

As shown in Table 3.6, most beneficiaries reported receiving hemodialysis (93.7 percent), while the remaining 6.3 percent of beneficiaries reported receiving peritoneal dialysis.

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<sup>5</sup> Even if sampling did not include those respondents who received their dialysis in a hospital setting, a small percentage of respondents indicated that they access dialysis in a hospital.

**Table 3.6: Type of Dialysis Treatment**

Type of Dialysis	Percent Beneficiaries
Hemodialysis	93.7
Peritoneal dialysis	6.3
TOTAL	100.0

A small number of beneficiaries reported receiving in-center peritoneal dialysis, but this population did not include a sufficient number to support subgroup analysis.

Less than 8 percent of ESRD beneficiaries reported dialyzing at home. Significant patient characteristics within this modality may help identify potential barriers to accessing at-home dialysis. The bivariate analysis shows that some subgroups reported at-home care at higher rates than other subgroups (Table 3.7). Overall, beneficiaries who were younger, White, non-Hispanic, not eligible for Medicaid, college educated, or in an urban environment had significantly higher rates of at-home dialysis than their counterparts.

Over 9 percent of beneficiaries aged 20-64 years reported dialyzing at home, compared with only 4.8 percent of beneficiaries aged 65 years and older. Twice as many beneficiaries with at least some college education reported at-home dialysis, compared with those with a high school degree or less. Younger adult ESRD beneficiaries (ages 20-64 years) and those with at least some college education may have higher rates of at-home dialysis than their counterparts due to at-home treatment requirements, such as adequate dexterity and vision and basic reading and writing skills.

Race/ethnicity was also a significant predictor of at-home dialysis. While 10.5 percent of White, non-Hispanic beneficiaries reported receiving dialysis at home, only 6.3 percent of non-White and Hispanic beneficiaries reported at-home treatment. In addition, dual Medicare/Medicaid eligible beneficiaries were less likely to report at-home dialysis (5.7 percent), compared with beneficiaries not receiving Medicaid (9.7 percent), and almost twice as many beneficiaries receiving care in urban areas reported at-home dialysis, compared with those receiving care in rural areas.



**Table 3.7: Percent of Beneficiaries Receiving At-Home Dialysis, by Selected Beneficiary Characteristics\***

Beneficiary Characteristics	Percent Beneficiaries
All beneficiaries	7.6
Race/ethnicity	
White, non-Hispanic	10.5*
Non-White or Hispanic	6.3*
Gender	
Male	7.1
Female	8.0
Age	
20-64 years	9.3*
65 years and older	4.8*
Education	
Some college or more	12.6*
High school degree or less	5.5*
Dual eligible status	
Yes	5.7*
No	9.7*
Facility location	
Urban	8.2*
Rural	4.8*
Facility ownership	
Non-profit	8.0
For-profit	7.4

\* $p \leq .05$

## At-Home Dialysis

This section presents findings for the subpopulation of ESRD beneficiaries who received at-home dialysis. Those beneficiaries who reported at-home dialysis were more equally distributed across treatment types than in-facility beneficiaries. As shown in Table 3.8, 79.9 percent of beneficiaries dialyzing at home reported receiving peritoneal dialysis, and 20.1 percent reported hemodialysis.

**Table 3.8: Percent of At-Home Beneficiaries by Type of Dialysis**

Type of Dialysis	Percent Beneficiaries
Hemodialysis	20.1
Peritoneal dialysis	79.9
TOTAL	100.0

In review of the patient characteristics for beneficiaries dialyzing at home, there were few significant differences (Table 3.9). This may be due to the relatively small sample size. Nearly half of beneficiaries receiving home dialysis care from non-profit facilities received home hemodialysis, compared with just 16.2 percent among those receiving care from for-profit facilities. Additionally,

more than a quarter of White, non-Hispanic beneficiaries dialyzing at home used hemodialysis, compared with 12.7 percent of non-White or Hispanic beneficiaries.

**Table 3.9: Percent of At-Home Beneficiaries Using Hemodialysis, by Selected Patient Characteristics\***

Beneficiary Characteristics	Percent Beneficiaries
All beneficiaries	20.1
Race/ethnicity	
White, non-Hispanic	<b>26.9*</b>
Non-White or Hispanic	<b>12.7*</b>
Gender	
Male	25.1
Female	15.2
Age	
20-64 years	21.3
65 years and older	16.3
Education	
Some college or more	22.9
High school degree or less	16.3
Dual eligible status	
Yes	13.9
No	24.5
Facility location	
Urban	19.7
Rural	23.3
Facility ownership	
Non-profit	<b>48.7*</b>
For-profit	<b>16.2*</b>

\* $p \leq .05$

## Treatment Time for In-Facility Hemodialysis

To assess the burden of dialysis treatment, we calculated a measure of total weekly treatment time for beneficiaries receiving in-facility hemodialysis. Total treatment time, as shown in Tables 3.10 and 3.11, includes number of days per week and length of time in in-facility hemodialysis. Virtually all in-facility hemodialysis beneficiaries reported dialyzing 3 days per week and 3 or 4 hours per session.

**Table 3.10: Days per Week Receiving Dialysis**

Number of Days per Week Receiving Dialysis	Percent Beneficiaries
1-2 days	1.1
3 days	98.1
4-5 days	0.80
TOTAL	100.0

**Table 3.11: Hours per Dialysis Treatment Session**

Length of Time in Dialysis	Percent Beneficiaries
2 hours per session	1.5
3 hours per session	43.9
4 hours per session	50.2
5 or more hours per session	4.4
TOTAL	100.0

For in-facility hemodialysis, there were no significant bivariate differences for total treatment time across beneficiary characteristics.

## **Dialysis Vascular Access Type**

Individuals receiving hemodialysis require temporary or permanent vascular access through a graft, fistula, or catheter. Permanent vascular access (grafts and fistulas) are recommended for most dialysis patients, as they reduce infection rates and improve overall dialysis outcomes. Fistulas are considered the gold standard in vascular access due to improved dialyzing performance and low blood clot and infection rates. Catheters are used for patients with emergency dialysis starts (often in-hospital), short-term dialysis, or patients unable to develop permanent access.

Beneficiaries reported the access type they used most often in the past 3 months. Among beneficiaries using hemodialysis, approximately 90 percent reported permanent vascular access through a fistula (62.8 percent) or a graft (27.9 percent). Only 10.1 percent reported dialyzing through a catheter (Table 3.12).

**Table 3.12: Vascular Access for Hemodialysis Beneficiaries**

Vascular Access	Percent of Beneficiaries
Graft	27.9
Fistula	62.8
Catheter	10.1
TOTAL	100.0

Table 3.13 presents selected beneficiary characteristics associated with the use of a fistula by hemodialysis patients. Significant differences were found when comparing fistula and graft. Men were significantly more likely to report using a fistula than women. Research suggests women's veins may be less amenable to the fistula development process (Allon, et al., 2001), contributing to this difference.

Similar to dialysis modality findings, race/ethnicity and education were significant predictors of fistula use. An estimated 77 percent of White non-Hispanic ESRD beneficiaries reported using a fistula, compared with 66.3 percent of non-White or Hispanic beneficiaries. ESRD beneficiaries with at least some college education had significantly higher fistula rates than beneficiaries with high school or less education, and almost 80 percent of ESRD beneficiaries at non-profit facilities reported having a fistula, compared with less than 69 percent of beneficiaries receiving care at for-profit facilities.

**Table 3.13: Fistula Access for Hemodialysis Beneficiaries,  
by Selected Patient Characteristics\***

<b>Beneficiary Characteristics</b>	<b>Percent of Beneficiaries With Fistula</b>
All beneficiaries	62.8
Race/ethnicity	
White, non-Hispanic	<b>77.0*</b>
Non-White or Hispanic	<b>66.3*</b>
Gender	
Male	<b>76.2*</b>
Female	<b>62.9*</b>
Age	
20-64 years	70.6
65 years and older	68.7
Education	
Some college or more	<b>75.7*</b>
High school degree or less	<b>67.3*</b>
Dual eligible status	
Yes	68.5
No	71.5
Facility location	
Urban	70.9
Rural	65.5
Facility ownership	
Non-profit	<b>79.5*</b>
For profit	<b>68.7*</b>

\* $p \leq .05$

### 3.1.3 Quality of Care

#### ***Highlights***

- At-home dialysis beneficiaries reported positive ratings for quality of care that were between 7.5 and 18.6 percentage points higher than in-facility dialysis beneficiaries.
- A greater percent of beneficiaries in good or better physical health reported that their kidney doctors listened carefully (85.8 percent) and were understandable (83.3 percent), compared with beneficiaries reporting worse physical health status (78.7 percent and 74.2 percent).
- Beneficiaries dialyzing at home, younger beneficiaries, and those with some college or more education reported higher rates of shared decision-making.

The Beneficiary Survey included questions about quality of care that examined beneficiary communication with the kidney doctors and kidney care team and asked about shared decision-making. Responding to CMS’s research question about the impact across various population groups, we looked carefully at the experiences of potentially vulnerable populations. To assess these experiences of care, we explored variations across important analytic subpopulations of ESRD beneficiaries, including dialysis setting, age, race, facility type and ownership, and self-reported physical health status.

#### ***Communication***

This section examines beneficiaries’ experiences communicating with their kidney care providers, both the kidney doctors as well as the broader care team. Questions looked specifically at the physician’s or team’s ability to listen carefully, explain concepts effectively, convey courtesy and respect, spend sufficient time with the beneficiary, and share in decision-making.

Most beneficiaries responded positively to questions about communication with their kidney doctors. Tables 3.14-3.21 describe beneficiary responses to questions regarding communication with their kidney doctors.

Beneficiaries also reported positively on questions about communication with their kidney care team. Tables 3.22-3.25 describe beneficiary responses to questions regarding communication with their kidney care team.

For many of the communication questions, ESRD beneficiaries reported statistically different experiences by treatment location (at-home vs. facility-based dialysis). Differences were also noted by self-reported physical health and age, as shown in the tables that follow. Beneficiaries' experience with their physicians and kidney care teams varied, particularly between at-home and facility-based dialysis beneficiaries.

### ***Perceived Careful Listening by Kidney Doctors***

The Beneficiary Survey asked, *“In the last 3 months, how often did your kidney doctors listen carefully to you?”* The majority of beneficiaries reported that their doctors “Usually” or “Always” listened carefully (Table 3.14).

**Table 3.14: Kidney Doctors Listened Carefully**

<b>Kidney Doctors Listen Carefully</b>	<b>Percent Beneficiaries</b>
Never	2.2
Sometimes	14.9
Usually	14.9
Always	68.0
TOTAL	100.0

Breaking this concept down by beneficiary characteristics, we found that significantly different experiences were reported by dialysis location, race/ethnicity, education level, and physical health status (Table 3.15). Beneficiaries dialyzing at home were more likely to report that their kidney doctors listen to them carefully. More than 95 percent of the at-home beneficiaries indicated that their kidney doctors “Usually” or “Always” listened carefully to them, compared with 81.8 percent of facility-based beneficiaries.

Of White, non-Hispanic beneficiaries, 86.1 percent reported that their kidney doctors “Usually” or “Always” listened carefully to them, compared with 81.0 percent of non-White or Hispanic beneficiaries. Beneficiaries with higher self-reported physical health were also more likely to report that their kidney doctors listen carefully to them. Almost 86 percent of beneficiaries who rated their physical health as “Good” or better reported that their kidney doctors “Usually” or “Always” listened carefully to them. In comparison, only 78.7 percent of beneficiaries with “Fair” or worse health rating reported careful listening of their kidney doctors.

**Table 3.15: Perceived Careful Listening, by Selected Patient Characteristics\***

Beneficiary Characteristics	Doctors “Usually” or “Always” Listen Carefully
	Percent Beneficiaries
All beneficiaries	82.9
Race/ethnicity	
White, non-Hispanic	<b>86.1*</b>
Non-White or Hispanic	<b>81.0*</b>
Gender	
Male	82.2
Female	83.7
Age	
20-64 years	83.5
65 years and older	81.9
Education	
Some college or more	<b>87.0*</b>
High school degree or less	<b>80.7*</b>
Dual eligible status	
Yes	81.8
No	84.2
Facility location	
Urban	82.8
Rural	83.3
Facility ownership	
Non-profit	83.5
For-profit	82.8
Dialysis location	
At-home	<b>95.6*</b>
In-facility	<b>81.8*</b>
Self-reported physical health status	
Good or better	<b>85.8*</b>
Fair or worse	<b>78.7*</b>

\* $p \leq .05$



## Ability to Understand Kidney Doctors

Nearly two-thirds of ESRD beneficiaries reported that their kidney doctors “Always” explained things in a way that was easy to understand (Table 3.16). About 79 percent of beneficiaries reported that their kidney doctors were “Usually” or “Always” understandable.

**Table 3.16: Kidney Doctors Explained Things  
in a Way That Was Easy to Understand**

Frequency	Percent Beneficiaries
Never	5.4
Sometimes	15.3
Usually	14.8
Always	64.5
TOTAL	100.0

In keeping with other communication questions, a greater number of beneficiaries dialyzing at home and those reporting better health status reported that their kidney doctors explained things in a way that was easy to understand (Table 3.17). Nearly all beneficiaries dialyzing at home reported that kidney doctors were “Usually” or “Always” understandable, compared with 77.9 percent of facility-based beneficiaries. Additionally, more than 83 percent of beneficiaries rating their physical health as “Good” or better reported that their kidney doctors were “Usually” or “Always” understandable, compared with 74.2 percent of less healthy beneficiaries. More than 82 percent of beneficiaries age 64 or younger “Usually” or “Always” found their doctors easy to understand, compared with just 74.2 percent of beneficiaries age 65 years and older. Beneficiaries with at least some college or more reported that they usually or always understood their kidney doctors more often (85.5 percent) compared to those beneficiaries with a high school degree or less (76.3 percent).

**Table 3.17: Ability to Understand the Kidney Doctors,  
by Selected Patient Characteristics\***

Beneficiary Characteristics	Doctors “Usually” or “Always” Understandable
	Percent Beneficiaries
All beneficiaries	79.3
Race/ethnicity	
White, non-Hispanic	81.9
Non-White or Hispanic	78.1
Gender	
Male	79.2
Female	79.4
Age	
20-64 years	<b>82.3*</b>
65 years and older	<b>74.2*</b>
Education	
Some college or more	<b>85.5*</b>
High school degree or less	<b>76.3*</b>
Dual eligible status	
Yes	77.5
No	81.5
Facility location	
Urban	78.9
Rural	81.0
Facility ownership	
Non-profit	81.3
For-profit	79.0
Dialysis location	
At-home	<b>95.5*</b>
Facility-based	<b>77.9*</b>
Self-reported physical health status	
Good or better	<b>83.3*</b>
Fair or worse	<b>74.2*</b>

\* $p \leq .05$

### ***Kidney Doctors Show Respect***

Beneficiaries were asked “*In the last 3 months, how often did your kidney doctors show respect for what you had to say?*” Slightly over three quarters of beneficiaries reported that their kidney doctors “Always” respected what they said (Table 3.18).

**Table 3.18: Kidney Doctors Showed Courtesy and Respect**

Frequency	Percent Beneficiaries
Never	3.1
Sometimes	10.9
Usually	11.0
Always	75.1
TOTAL	100.0

As in the prior communication questions, more beneficiaries dialyzing at home reported that their kidney doctors demonstrated good communication skills related to respectful listening (Table 3.19). Almost 98 percent of those receiving dialysis at home reported that their kidney doctors “Usually” or “Always” showed respect for what they had to say, compared with just 85.1 percent among facility-based beneficiaries. Healthier beneficiaries were statistically more likely to report that their kidney doctors showed respect, although the difference was not large. Higher education was also significant in the bivariate analysis where beneficiaries with some college or more indicated that their doctors showed respectful listening at 89.9 percent, compared to those with a high school degree or less (83.9 percent).

**Table 3.19: Kidney Doctors Showed Courtesy and Respect  
by Selected Patient Characteristics\***

<b>Beneficiary Characteristics</b>	<b>Percent Beneficiaries</b>
All beneficiaries	86.1
Race/ethnicity	
White, non-Hispanic	87.3
Non-White or Hispanic	84.8
Gender	
Male	86.1
Female	86.0
Age	
20-64 years	86.4
65 years and older	85.5
Education	
Some college or more	<b>89.9*</b>
High school degree or less	<b>83.9*</b>
Dual eligible status	
Yes	85.1
No	87.2
Facility location	
Urban	86.0
Rural	86.3
Facility ownership	
Non-profit	89.5
For-profit	85.7
Dialysis location	
At-home	<b>97.7*</b>
Facility-based	<b>85.1*</b>
Self-reported physical health status	
Good or better	<b>87.5*</b>
Fair or worse	<b>83.8*</b>

\* $p \leq .05$

## ***Adequate Time With Kidney Doctors***

Beneficiaries were asked “*In the last 3 months, how often did your kidney doctors spend enough time with you?*” More than half of beneficiaries reported that their kidney doctors “Always” spent enough time with them (Table 3.20).

**Table 3.20: Kidney Doctors Spent Enough Time with You**

Frequency	Percent Beneficiaries
Never	5.7
Sometimes	19.2
Usually	22.2
Always	52.9
TOTAL	100.0

Beneficiaries receiving dialysis at home were considerably more likely to report that their kidney doctors spent enough time with them (Table 3.21). More than 92 percent of those dialyzing at home felt that their kidney doctors “Usually” or “Always” spent enough time, compared with only 73.7 percent of facility-based beneficiaries. Healthier beneficiaries were also significantly more likely to report that their kidney doctors spent enough time with them. More than 78 percent of beneficiaries rating their physical health as “Good” or better reported that their kidney doctors “Usually” or “Always” spent enough time with them. In comparison, only 70.7 percent of less healthy beneficiaries reported adequate time. Significant differences on kidney doctors “Usually” or “Always” spending enough time were also found by race/ethnicity and level of education.

**Table 3.21: Kidney Doctors Spent Enough Time,  
by Selected Patient Characteristics\***

<b>Beneficiary Characteristics</b>	<b>Percent Beneficiaries</b>
All beneficiaries	75.1
Race/ethnicity	
White, non-Hispanic	<b>78.2*</b>
Non-White or Hispanic	<b>73.8*</b>
Gender	
Male	75.4
Female	74.8
Age	
20-64 years	76.4
65 years and older	73.0
Education	
Some college or more	<b>80.1*</b>
High school degree or less	<b>72.4*</b>
Dual eligible status	
Yes	74.2
No	76.2
Facility location	
Urban	74.9
Rural	76.0
Facility ownership	
Non-profit	74.5
For-profit	75.1
Dialysis location	
At-home	<b>92.3*</b>
Facility-based	<b>73.7*</b>
Self-reported physical health status	
Good or better	<b>78.6*</b>
Fair or worse	<b>70.7*</b>

\* $p \leq .05$

### ***Kidney Care Team's Courtesy and Respect***

Recognizing the importance of team-based care delivery, in addition to reporting on their experiences with kidney care doctors, ESRD beneficiaries were asked about their interactions with the kidney care team as a whole. Beneficiaries were asked “*In the last 3 months, how often did your kidney care team treat you with courtesy and respect?*” More than 90 percent of beneficiaries reported that their care team “Usually” or “Always” treated them with respect (Table 3.22).

**Table 3.22: Kidney Care Team Showed Courtesy and Respect**

Frequency	Percent Beneficiaries
Never	0.8
Sometimes	8.8
Usually	18.4
Always	72.1
TOTAL	100.0

When considering differences across beneficiary subgroups, treatment location and dual eligibility were the only characteristics across which significant differences were noted for the kidney care team’s courtesy and respect (Table 3.23). More than 97 percent of the beneficiaries receiving dialysis at home indicated that their care team “Usually” or “Always” treated them with courtesy and respect. Among facility-based beneficiaries, the rate was significantly lower (89.8 percent). There are also significant differences between dual and non-dual eligible beneficiaries,, where those without Medicaid indicated that their kidney care team “Usually” or “Always” showed them courtesy and respect (92.4 percent) compared to dual eligible beneficiaries at 88.7 percent.

**Table 3.23: Kidney Care Team Showed Courtesy and Respect, by Selected Patient Characteristics\***

Beneficiary Characteristics	Percent Beneficiaries
All beneficiaries	90.4
Race/ethnicity	
White, non-Hispanic	93.0
Non-White or Hispanic	89.7
Gender	
Male	90.8
Female	90.0
Age	
20-64 years	89.7
65 years and older	91.7
Education	
Some college or more	91.7
High school degree or less	90.1
Dual eligible status	
Yes	<b>88.7*</b>
No	<b>92.4*</b>
Facility location	
Urban	90.3
Rural	91.0
Facility ownership	
Non-profit	92.1
For-profit	90.2
Dialysis location	
At-home	<b>97.4*</b>
Facility-based	<b>89.8*</b>
Self-reported physical health status	
Good or better	91.1
Fair or worse	89.5

\* $p \leq .05$

## Kidney Care Team Spent Enough Time

Beneficiaries receiving dialysis in a facility were asked “*In the last 3 months, how often did your kidney care team spend enough time with you?*” Close to 83 percent of beneficiaries reported that their care team “Usually” or “Always” spent enough time with them (Table 3.24).

**Table 3.24: Kidney Care Team Spent Enough Time with You**

Frequency	Percent Beneficiaries
Never	2.4
Sometimes	14.7
Usually	22.8
Always	60.0
TOTAL	100.0

Beneficiaries with self-reported physical health of “Good” or better were more likely to report that their care team “Usually” or “Always” spent enough time with them (85.6 percent, compared with 80.1 percent for those with lower health ratings) (Table 3.25). Exactly 88 percent of White, non-Hispanic beneficiaries reported that their care team “Usually” or “Always” spent enough time with them, compared with 80.4 percent of non-White or Hispanic beneficiaries.

**Table 3.25: Kidney Care Team Spent Enough Time, by Selected Patient Characteristics\***

Beneficiary Characteristics	Percent Beneficiaries
All beneficiaries	82.8
Race/ethnicity	
White, non-Hispanic	<b>88.0*</b>
Non-White or Hispanic	<b>80.4*</b>
Gender	
Male	83.0
Female	82.6
Age	
20-64 years	83.1
65 years and older	82.4
Education	
Some college or more	85.2
High school degree or less	81.7
Dual eligible status	
Yes	82.0
No	83.8
Facility location	
Urban	82.1
Rural	85.9
Facility ownership	
Non-profit	84.7
Non-profit	82.5



**Table 3.25: Kidney Care Team Spent Enough Time, by Selected Patient Characteristics\* (continued)**

Beneficiary Characteristics	Percent Beneficiaries
Dialysis location	
At-home	**
Facility-based	82.8
Self-reported physical health status	
Good or better	<b>85.6*</b>
Fair or worse	<b>80.1*</b>

\* $p \leq .05$

\*\* Beneficiaries receiving dialysis at home skipped this question.

### ***Shared Decision-Making***

The survey asked beneficiaries to assess their providers' engagement in shared decision-making. For those beneficiaries who made a decision regarding starting or stopping a prescription medicine, the survey asked about the degree to which beneficiaries were involved in decision-making regarding that change in prescription. Beneficiaries were asked, *"In the last 3 months, did you and your kidney doctors talk about starting or stopping a prescription medicine?"*

Almost 40 percent of beneficiaries reported that they discussed either starting or stopping medication (Table 3.26). Beneficiaries who made a decision were asked three follow-up questions about the advantages and disadvantages of prescription medicines and whether they were asked what was best for them. While 88.2 percent of beneficiaries reported talking with their doctors about the "pros" or reasons they would want to take the prescription, only 68.5 reported talking about the "cons" or reasons not to take the prescription. Fully 71.8 percent of beneficiaries indicated that they discussed what was best for them.

**Table 3.26: Kidney Doctors Discussed Pros, Cons, and What Was Best for Beneficiary**

<b>“Did You and Your Kidney Doctors Talk About ...”</b>	<b>Percent Beneficiaries Reporting “Yes”</b>
... starting or stopping a prescription medicine?	38.8
... the reasons why you might want to take the prescription medicine? *	88.2
... the reasons why you might not want to take the prescription medicine? *	68.5
... what you thought was best for you when starting or stopping a prescription medicine? *	71.8

\*Denominator excludes those who did not discuss starting or stopping a prescription medicine.

Among the beneficiaries who discussed starting or stopping a prescription medication, 95.8 percent of beneficiaries receiving dialysis at home reported reviewing the benefits of the prescription with their kidney doctor, compared with 87.2 percent of those receiving dialysis in a facility (Table 3.27). Beneficiaries receiving dialysis at home were also more likely to report that doctors asked what was best for them regarding their medication changes (78.9 percent, compared with 70.8 percent of those receiving dialysis in a facility). These findings are consistent with the communication results, in which beneficiaries dialyzing at home were more likely to report positive physician and kidney care team interactions.

In keeping with other communication results, beneficiaries with self-reported health of “Good” or better were more likely to indicate that their kidney doctors asked their opinion about prescriptions (78.6 percent, compared with just 62.8 percent of those with poorer health ratings) (Table 3.27). Interestingly, self-reported physical health status was not significantly different for other measures of shared decision-making.

Rates of shared decision-making also varied significantly by age. Among the beneficiaries reporting an initial discussion about prescription medication, 91.4 percent of younger beneficiaries reported discussing the benefits, compared with 81.3 percent of older beneficiaries. Similarly, 72.8 percent of younger beneficiaries discussed the disadvantages, compared with only 59.0 percent of older beneficiaries.

Beneficiaries with higher levels of education were more likely to discuss reasons for taking a prescription medicine (91.8 percent) than those who had a high school degree or less (86.0). Significant differences in education also appeared when beneficiaries discussed with their physician not taking a prescription medication.

**Table 3.27: Shared Decision-Making, by Significant Patient Characteristics\***

<b>Beneficiary Characteristics</b>	<b>Discussed Reasons to Take the Prescription Medicine**</b>	<b>Discussed Reasons Not to Take the Prescription Medicine**</b>	<b>Discussed What You Thought Was Best for You**</b>
All beneficiaries	88.2	68.5	71.8
Race/ethnicity			
White, non-Hispanic	89.0	72.2	75.3
Non-White or Hispanic	87.8	67.6	69.5
Gender			
Male	88.4	70.0	70.8
Female	88.1	67.0	72.9
Age			
20-64 years	<b>91.4*</b>	<b>72.8*</b>	73.1
65 years and older	<b>81.3*</b>	<b>59.0*</b>	69.1
Education			
Some college or more	<b>91.8*</b>	<b>76.0*</b>	72.8
High school degree or less	<b>86.0*</b>	<b>63.6*</b>	71.1
Dual eligible status			
Yes	87.6	68.9	71.7
No	88.9	68.1	72.0
Facility location			
Urban	87.3	68.9	70.5
Rural	92.6	66.8	78.1
Facility ownership			
Non-profit	91.4	70.8	78.8
For-profit	87.7	68.1	70.7
Dialysis location			
At-home	<b>95.8*</b>	74.0	<b>78.9*</b>
Facility-based	<b>87.2*</b>	67.7	<b>70.8*</b>
Self-reported physical health status			
Good or better	90.1	68.7	<b>78.6*</b>
Fair or worse	86.0	68.2	<b>62.8*</b>

\* $p \leq .05$

\*\* Denominator excludes those who did not discuss starting or stopping a prescription medicine.

### 3.1.4 Beneficiary Education

#### Highlights

- Beneficiaries who were younger, those who reported better physical health status, and those who dialyzed at home reported receiving more educational outreach.
- Most beneficiaries (93.5 percent) reported dietary self-care education, with minimal variations in education frequency among subgroups.
- Beneficiaries receiving dialysis at a non-profit facility were more positive about their kidney doctors or care team speaking to them about their mental or emotional health (73.4 percent) compared to those at a for-profit facility (64.5 percent).

Education plays a critical role in dialysis care, as kidney failure is a multifaceted health issue, treatment options are complex, and self-care is essential. Furthermore, patient education needs to be ongoing to periodically encourage dialysis patients to reassess their treatment options. For these reasons, the Beneficiary Survey included a series of questions on beneficiary education.

Survey questions asked whether the doctor or care team discussed why a beneficiary was not eligible for a kidney transplant (where applicable) and whether the doctor or care team discussed the topics of transplantation and peritoneal dialysis as much as the beneficiary wanted. The survey also included questions about whether the doctor or care team covered the topics of nutrition and managing health, and offered support in achieving health-related goals.

#### Kidney Transplant

In addition to hemodialysis and peritoneal dialysis, beneficiaries can consider kidney transplant as an ESRD treatment. Transplantation is covered by Medicare, and some people think that it can yield a better quality of life because it may mean greater freedom, more energy, and a less-restrictive diet. While transplantation is not a viable treatment for all ESRD beneficiaries, nearly half of all beneficiaries reported that they were ineligible for kidney transplant (Table 3.28).

**Table 3.28: Eligibility for Kidney Transplant**

Perceived Transplant Eligibility	Percent of Beneficiaries
Yes	52.2
No	47.8
TOTAL	100.0

Beneficiaries who perceived that they were ineligible for transplant were asked if anyone explained why they were not eligible. Surprisingly, less than half of the beneficiaries reported that this treatment option had been discussed with them (Table 3.29). Beneficiaries were also asked, “*In the last 12 months, did your kidney doctors or anyone on your kidney care team talk with you as much as you wanted about a kidney transplant?*” Slightly more than half reported that their doctors or care team provided as much transplant education as they wanted.

**Table 3.29: Kidney Transplant Education**

<b>Kidney Transplant Education</b>	<b>Percent Beneficiaries Reporting “Yes”</b>
Kidney doctors or care team explain why you are not eligible for a kidney transplant*	46.6
Kidney doctors or care team talk with you as much as you wanted about a kidney transplant*	51.0

\*Denominator excludes those who stated they are eligible for transplant.

Younger beneficiaries were more likely to report that providers explained transplantation eligibility (51.7 percent) compared with beneficiaries age 65 years and older (41.9 percent) (Table 3.30). Younger beneficiaries were also more likely to report higher rates of transplantation education (59.4 percent) compared with beneficiaries age 65 years and older (43.1 percent).

Among beneficiaries receiving dialysis at home, more than 68 percent reported that their providers discussed transplantation as much as they wanted, compared with 49.8 percent of beneficiaries dialyzing in a facility. Kidney transplant education also varied significantly by race/ethnicity; over 55 percent of White, non-Hispanic beneficiaries reported that their providers discussed transplant as much as they wanted, compared with 47.3 percent beneficiaries of other racial or ethnic groups.

Some variation in education frequency may reflect the doctor or kidney care team’s assessment of successful transplant candidacy. Younger dialysis patients and those with fewer comorbidities may be better candidates due to transplant requirements. Kidney providers may discuss transplant more frequently with patients they perceive as strong candidates. Furthermore, higher reported rates of transplant education for at-home patients may reflect bias in the at-home population. Generally, at-home patients have higher rates of medical stability, compliance, and self-care, which are important when evaluating a patient for transplant.

**Table 3.30: Transplant Education, by Selected Patient Characteristics\***

Beneficiary Characteristics	Percent Beneficiaries Reporting “Yes”	
	Kidney Doctors or Care Team Explain Why You Are Not Eligible for a Kidney Transplant**	Kidney Doctors or Care Team Talk With You as Much as You Wanted About a Kidney Transplant**
All beneficiaries	46.6	51.0
Race/ethnicity		
White, non-Hispanic	46.4	55.2*
Non-White or Hispanic	46.7	47.3*
Gender		
Male	48.6	50.5
Female	44.7	51.4
Age		
20-64 years	51.7*	59.4*
65 years and older	41.9*	43.1*
Education		
Some college or more	49.4	53.7
High school degree or less	44.9	49.0
Dual eligible status		
Yes	49.6	51.5
No	43.7	50.5
Facility location		
Urban	47.4	49.6
Rural	43.4	57.1
Facility ownership		
Non-profit	50.6	57.0
For-profit	46.2	50.1
Dialysis location		
At-home	48.7	68.6*
Facility-based	46.5	49.8*
Self-reported physical health status		
Good or better	45.5	53.8*
Fair or worse	47.7	46.6*

\*p≤.05.

\*\*Denominator excludes those who stated they are eligible for transplant.

## Dialysis Modality and Self-Care Education

Dialysis modality and self-care are two critical components of successful ESRD treatment that require ongoing education. Beneficiaries receiving hemodialysis were asked if anyone talked with them about peritoneal dialysis. Slightly more than 60 percent of beneficiaries agreed that their doctors discussed dialysis modality as much as they wanted (Table 3.31). In addition, beneficiaries were asked, “*In the last 3 months, did your kidney doctors or anyone on your kidney care team talk to you about what you should eat and drink?*” Nearly all beneficiaries (93.5 percent) reported receiving dietary self-care education.

**Table 3.31: Treatment Modality and Self-Care Education**

Treatment Modality and Self-Care Education	Percent Beneficiaries Reporting “Yes”
Kidney doctors or care team talk with you as much as you wanted about peritoneal dialysis	60.4
Kidney doctors or care team talk to you about what you should eat and drink	93.5

As discussed regarding education on transplants, some differences in education rates may reflect the likelihood that the beneficiary is a viable candidate for peritoneal dialysis. Younger beneficiaries and those who reported their physical health as “Good” or better were significantly more likely to report that their doctors discussed peritoneal dialysis as much as they wanted (Table 3.32).

Differences in treatment modality education were also found by facility. Over 70 percent of beneficiaries in rural facilities reported discussing peritoneal dialysis as frequently as desired, compared with only 58.1 percent of beneficiaries in urban facilities.

Dietary and fluid restrictions are a critical component of successful dialysis care, and therefore self-care education about what a beneficiary can eat and drink is essential. Overall, beneficiaries reported high rates of self-care education, and the variations by subgroup were minimal. Self-care education was significantly different for beneficiaries dialyzing at home versus those dialyzing at a facility. However, the difference between this subgroup was less than 5 percent.

**Table 3.32: Treatment Modality and Self-Care Education, by Selected Patient Characteristics\***

Beneficiary Characteristics	Percent Beneficiaries Reporting “Yes”	
	Talk With You as Much as You Wanted About Peritoneal Dialysis	Talk to You About What You Should Eat and Drink
All beneficiaries	60.4	93.5
Race/ethnicity		
White, non-Hispanic	60.3	95.1
Non-White or Hispanic	60.8	92.8
Gender		
Male	61.0	93.3
Female	59.6	93.8
Age		
20-64 years	<b>65.3*</b>	94.2
65 years and older	<b>52.4*</b>	92.5
Education		
Some college or more	62.5	93.7
High school degree or less	59.7	93.2
Dual eligible status		
Yes	62.8	92.8
No	57.3	94.4
Facility location		
Urban	<b>58.1*</b>	93.2
Rural	<b>70.7*</b>	94.9
Facility ownership		
Non-profit	56.9	93.6
For-profit	60.7	93.5
Dialysis location		
At-home	64.5	<b>98.0*</b>
Facility-based	60.3	<b>93.2*</b>
Self-reported physical health status		
Good or better	<b>63.5*</b>	94.2
Fair or worse	<b>56.0*</b>	92.5

\*  $p \leq .05$ .



## Health Management Goals

Self-management support is of growing importance across all health settings, including organizations servicing patients with ESRD. To assess the degree of self-management support being offered, beneficiaries were asked, “*In the last 3 months, did your kidney doctors or anyone on your kidney care team work with you to set specific goals for managing your health?*” Over 80 percent reported that they were provided with this support (Table 3.33). Of those beneficiaries who received help to set goals, 91.6 percent also reported that members of their kidney care team offered them help to reach the goals.

**Table 3.33: Health Management Goal Setting**

	Percent Beneficiaries Reporting “Yes”
Kidney doctors or care team work with you to set specific goals for managing your health	81.1
Kidney doctors or care team offer you help to reach these goals*	91.6

\*Denominator excludes those who stated they did not set goals.

When considering health management goal-setting by patient characteristics, some significant differences were identified. Almost 92 percent of beneficiaries dialyzing at home reported that their providers worked with them to set goals for managing their health, compared with 80.2 percent of facility-based beneficiaries (Table 3.34). Similar to other dialysis education findings, beneficiaries reporting their physical health as “Good” or better were more likely than other beneficiaries to report that their providers helped set health management goals.

Of those beneficiaries who set health management goals, beneficiaries dialyzing at home, younger beneficiaries, those with some college or more education, and those with better physical health were more likely to report their kidney doctors or care team offered to help them reach their goals. However, the differences were not large.

**Table 3.34: Health Management Goal Setting and Assistance,  
by Selected Patient Characteristics\***

Beneficiary Characteristics	Percent Beneficiaries Reporting “Yes”	
	Kidney Doctors or Care Team Work with You to Set Specific Goals for Managing Your Health	Kidney Doctors or Care Team Offer You Help to Reach These Goals**
All beneficiaries	81.1	91.6
Race/ethnicity		
White, non-Hispanic	80.5	91.8
Non-White or Hispanic	81.3	91.9
Gender		
Male	81.0	90.7
Female	81.3	92.6
Age		
20-64 years	82.0	<b>93.2*</b>
65 years and older	79.5	<b>88.8*</b>
Education		
Some college or more	81.8	<b>94.3*</b>
High school degree or less	80.4	<b>90.2*</b>
Dual eligible status		
Yes	80.5	91.7
No	81.8	91.6
Facility location		
Urban	81.2	91.0
Rural	80.6	94.5
Facility ownership		
Non-profit	81.1	91.3
For-profit	81.0	91.6
Dialysis location		
At-home	<b>91.9*</b>	<b>95.6*</b>
Facility-based	<b>80.2*</b>	<b>91.2*</b>
Self-reported physical health status		
Good or better	<b>83.2*</b>	<b>93.7*</b>
Fair or worse	<b>78.3*</b>	<b>88.6*</b>

\*p≤.05.

\*\*Denominator excludes those who stated they did not set goals.

## Comprehensiveness of Care

The Beneficiary Survey included a pair of questions on the comprehensiveness of care, which is to say, the intersection of physical and emotional health, also referred to as “whole person orientation.” Survey questions asked *“In the last 3 months, did your kidney doctors or anyone on your kidney care team ask you about your mental or emotional health?”* and *“In the last 3 months, did your kidney doctors or anyone on your kidney care team ask you about how your kidney disease affects other parts of your life?”*

More than 65 percent of beneficiaries reported that their doctors or care teams inquired about their mental or emotional health in the past 3 months. Similarly, slightly more than 66 percent of beneficiaries reported that their kidney doctors or kidney care team asked them how their kidney disease affected other parts of life (Table 3.35).

**Table 3.35: Comprehensiveness of Care**

Quality of Life	Percent Beneficiaries Reporting “Yes”
Kidney doctors or care team ask about mental or emotional health	65.5
Kidney doctors or care team ask how your kidney disease affects other parts of your life	66.1

When further assessing comprehensiveness of care by subgroups, several significant differences were identified (Table 3.36). While more than 80 percent of beneficiaries dialyzing at home reported being asked about their mental or emotional health, only 64.3 percent of facility-based beneficiaries reported this same comprehensiveness.

This finding could suggest that beneficiaries who dialyze at home and schedule office visits with their kidney care team make use of their time with health care professionals to discuss overarching health matters. In contrast, those who dialyze in facility overlap with the care team to receive dialysis multiple times per week, but do not necessarily have time set aside for broader health discussions. In addition, beneficiaries receiving dialysis at a non-profit facility were more likely to report that their kidney doctors or care team asked about their mental or emotional health (73.4 percent) compared to those beneficiaries receiving dialysis at a for-profit facility (64.5 percent).

Significant differences in comprehensiveness of care were also identified by health status, age, and race/ethnicity. These differences, however, were much smaller, as shown in Table 3.36.

**Table 3.36: Comprehensiveness of Care, by Selected Patient Characteristics\***

Beneficiary Characteristics	Percent Beneficiaries Reporting “Yes”	
	Kidney Doctors or Care Team Ask About Your Mental or Emotional Health	Kidney Doctors or Care Team Ask About How Kidney Disease Affects Other Parts of Your Life
All beneficiaries	65.5	66.1
Race/ethnicity		
White, non-Hispanic	<b>62.3*</b>	64.2
Non-White or Hispanic	<b>67.1*</b>	67.3
Gender		
Male	65.4	66.6
Female	65.7	65.6
Age		
20-64 years	<b>67.9*</b>	<b>68.2*</b>
65 years and older	<b>61.5*</b>	<b>62.6*</b>
Education		
Some college or more	64.3	64.0
High school degree or less	65.8	66.8
Dual eligible status		
Yes	66.6	66.9
No	64.3	65.2
Facility location		
Urban	64.6	65.4
Rural	69.9	69.6
Facility ownership		
Non-profit	<b>73.4*</b>	68.8
For-profit	<b>64.5*</b>	65.9
Dialysis location		
At-home	<b>80.9*</b>	<b>74.9*</b>
Facility-based	<b>64.3*</b>	<b>65.4*</b>
Self-reported physical health status		
Good or better	<b>68.7*</b>	<b>69.4*</b>
Fair or worse	<b>61.2*</b>	<b>61.9*</b>

\* $p \leq .05$ .

### 3.1.5 Outcomes

#### Highlights

- Beneficiaries age 65 or older reported fewer inpatient hospital days (0.48 days) than beneficiaries aged 20-64 years (0.69 days).
- Beneficiaries aged 20-64 were significantly more likely to report one or more dialysis-related infections in the previous 3 months (12.3 percent) compared to those 65 and older (8.4 percent).

This section describes beneficiaries' self-reported health outcomes, including hospitalizations (inpatient and outpatient) and dialysis-related infections.

#### Hospitalizations

Thirty percent of beneficiaries received outpatient hospital care at least once in the prior 3 months (Table 3.37). Almost thirty percent of beneficiaries also reported receiving inpatient hospital care in the prior 3 months.

**Table 3.37: Hospitalizations in Prior 3 Months**

Number of Days	Self-Reported Hospitalizations	
	Percent Inpatient	Percent Outpatient
None	70.3	70.0
1 to 5 days	17.6	28.6
6 or more days	12.2	1.4
TOTAL	100.0	100.0

Self-reported hospitalizations were further examined by age, race, gender, treatment modality, vascular access, total treatment time, and facility ownership. The only variable significantly related to hospitalization was beneficiary age. Beneficiaries aged 65 or older reported fewer inpatient hospital days (average of 0.48 days) compared with beneficiaries aged 20-64 years (average of 0.69 days). There were no significant differences related to the other beneficiary characteristics.

#### Dialysis-Related Infections

Beneficiaries were also asked to report the number of dialysis-related infections they contracted. Almost 90 percent of beneficiaries reported no infections in the prior 3 months, and only 4 percent reported contracting two or more infections (Table 3.38).

**Table 3.38: Dialysis-Related Infections in Prior 3 Months**

Number of infections	Percent Beneficiaries
None	89.2
One	6.9
Two or more	4.0
TOTAL	100.0

Some beneficiary groups had higher rates of dialysis-related infections. As expected, these included younger beneficiaries, and those with a self-reported health status of fair or worse (Table 3.39).

**Table 3.39: Dialysis-Related Infections in Prior 3 Months  
by Selected Beneficiary Characteristics\***

Beneficiary Characteristics	Percent Beneficiaries with at Least One Dialysis-Related Infection
All beneficiaries	10.9
Race/ethnicity	
White, non-Hispanic	10.7
Non-White or Hispanic	11.0
Gender	
Male	11.8
Female	9.8
Age	
20-64 years	<b>12.3*</b>
65 years and older	<b>8.4*</b>
Education	
Some college or more	11.0
High school degree or less	10.6
Dual eligible status	
Yes	12.0
No	9.5
Facility location	
Urban	11.3
Rural	9.0
Facility ownership	
Non-profit	9.8
For-profit	10.9
Dialysis location	
At-home	13.0
Facility-based	10.7
Self-reported physical health status	
Good or better	<b>9.1*</b>
Fair or worse	<b>13.2*</b>
Treatment modality	
Peritoneal	14.2
Hemodialysis	10.5

\*  $p \leq .05$ .

### 3.1.6 Quality of Life

#### Highlights

- Beneficiaries with self-reported physical health status of “Fair” or worse reported depressive symptoms and more burden from fluid and dietary restrictions at differences ranging from 12.7 to 18.4 percentage points higher than beneficiaries with self-reported physical health status of “Good” or better.
- Less than 10 percent of beneficiaries receiving at home dialysis reported “Usually” or “Always” feeling downhearted and blue, compared with over 16.3 percent of in-facility beneficiaries.

The Beneficiary Survey asked questions to assess quality of life, including the perceived burden of fluid and dietary restrictions and regularity of depressive symptoms. Successful dialysis requires self-care, which includes specific dietary and fluid restrictions that can be difficult to understand and challenging to adopt. Some patients may have a more difficult time sustaining the prescribed restrictions, particularly when the restrictions are perceived as burdensome. Furthermore, depressive symptoms can influence a patient’s self-care success, particularly if the patient has limited social support. These quality-of-life indicators not only impact beneficiaries’ well-being, but can influence treatment outcomes and overall health.

#### Fluid and Diet Restrictions

Approximately 30 percent of beneficiaries indicated that fluid or dietary restrictions never bothered them, and about 40 percent reported that restrictions sometimes bothered them (Table 3.40).

**Table 3.40: Burden of Fluid and Dietary Restrictions in Prior 3 Months**

Frequency	Percent Beneficiaries	
	Fluid Restrictions	Diet Restrictions
Never	28.4	32.1
Sometimes	40.8	40.5
Usually	13.1	11.3
Always	17.7	16.1
TOTAL	100.0	100.0

Bivariate analysis (presented in Table 3.41) showed that self-reported physical health status, dialysis location, dual eligibility, and facility location were significantly associated with beneficiaries “Usually” or “Always” being bothered by fluid restrictions. Significant differences in reported dietary restrictions were also seen by gender, with women more likely to report “Usually” or “Always” feeling burdened, as well as beneficiaries with self-perceived health status of “Fair” or worse.

Beneficiaries receiving hemodialysis were significantly more likely to report “Usually” or “Always” feeling burdened by fluid restrictions, compared with beneficiaries on peritoneal dialysis.

**Table 3.41: Perceived Burden of Fluid and Dietary Restrictions,  
by Selected Beneficiary Characteristics\***

Beneficiary Characteristics	Percent Beneficiaries Reported Fluid Restrictions “Usually” or “Always” Burdensome	Percent Beneficiaries Reported Dietary Restrictions “Usually” or “Always” Burdensome
All beneficiaries	30.8	27.4
Race/ethnicity		
White, non-Hispanic	28.9	24.6
Non-White or Hispanic	31.8	28.3
Gender		
Male	32.3	<b>25.4*</b>
Female	29.3	<b>29.5*</b>
Age		
20-64 years	32.5	28.0
65 years and older	28.2	26.3
Education		
Some college or more	30.9	28.0
High school degree or less	30.9	27.0
Dual eligible status		
Yes	<b>33.2*</b>	28.7
No	<b>28.0*</b>	25.8
Facility location		
Urban	<b>32.0*</b>	28.0
Rural	<b>25.4*</b>	24.5
Facility ownership		
Non-profit	26.9	23.2
For-profit	31.1	27.8
Dialysis location		
At-home	<b>20.5*</b>	27.5
Facility-based	<b>31.7*</b>	27.4
Self-reported physical health status		
Good or better	<b>22.9*</b>	<b>21.9*</b>
Fair or worse	<b>41.3*</b>	<b>34.6*</b>
Treatment modality		
Peritoneal	<b>21.9*</b>	27.8
Hemodialysis	<b>31.5*</b>	27.2

\*  $p \leq .05$ .



## Feeling Downhearted and Blue

Beneficiaries were asked, “*In the last 3 months how often have you felt downhearted and blue?*” Slightly over one-third of beneficiaries reported that they “Never” felt downhearted and blue, and a further half reported “Sometimes” having these feelings in the past 3 months (Table 3.42).

**Table 3.42: Frequency of Depressive Symptoms**

Felt Downhearted and Blue	Percent Beneficiaries
Never	34.2
Sometimes	50.0
Usually	8.4
Always	7.4
TOTAL	100.0

Across subgroups, there were significant differences in the frequency of self-reported depressive symptoms. Overall, male beneficiaries were more likely to report “Usually” or “Always” feeling downhearted and blue, compared with female beneficiaries (Table 3.43). In addition, White, non-Hispanic beneficiaries were less likely to report depressive symptoms than non-White or Hispanic beneficiaries. As expected, beneficiaries with self-reported health status of “Fair” or worse were more likely to feel downhearted and blue (23.9 percent) compared to those whose health status was “Good” or “Better” (9.6 percent).

When considering facility characteristics, beneficiaries dialyzing at home had more positive responses, with less than 10 percent “Usually” or “Always” feeling downhearted and blue, compared with over 16 percent of those in a facility setting. Additionally, significant differences were noted by facility ownership. About 10 percent of beneficiaries with non-profit organizations reported that they were “Usually” or “Always” downhearted and blue, compared with about 16.4 percent of beneficiaries at for-profit facilities.

**Table 3.43: Depressive Symptoms, by Selected Patient Characteristics**

<b>Beneficiary Characteristics</b>	<b>Percent Beneficiaries Who “Usually” or “Always” Felt Downhearted or Blue</b>
All beneficiaries	15.7
Race/ethnicity	
White, non-Hispanic	<b>13.1<sup>*</sup></b>
Non-White or Hispanic	<b>17.3<sup>*</sup></b>
Gender	
Male	<b>17.5<sup>*</sup></b>
Female	<b>13.8<sup>*</sup></b>
Age	
20-64 years	16.0
65 years and older	15.3
Education	
Some college or more	15.4
High school degree or less	15.9
Dual eligible status	
Yes	16.9
No	14.3
Facility location	
Urban	16.4
Rural	12.5
Facility ownership	
Non-profit	<b>10.2<sup>*</sup></b>
For-profit	<b>16.4<sup>*</sup></b>
Dialysis location	
At-home	<b>9.4<sup>*</sup></b>
Facility-based	<b>16.3<sup>*</sup></b>
Self-reported physical health status	
Good or better	<b>9.6<sup>*</sup></b>
Fair or worse	<b>23.9<sup>*</sup></b>
Treatment modality	
Peritoneal	11.1
Hemodialysis	16.1

<sup>\*</sup>  $p \leq .05$ .

### 3.1.7 Out-of-Pocket Costs

#### Highlights

- Over 65 percent of non-dual-eligible beneficiaries reported delaying treatment due to cost, compared with only 30.6 percent of dual-eligible beneficiaries.
- Non-dual-eligible beneficiaries (44.2 percent) were more likely to be worried about the cost of care than dual-eligible beneficiaries (35.2 percent).
- Beneficiaries dialyzing at home (28.3 percent) tended to speak more with their kidney doctors and kidney care team about the cost of care, compared with in-facility beneficiaries (16.1 percent).

The ESRD program under Medicare Part B covers 80 percent of outpatient treatment, including dialysis. Comprehensive care, including dialysis treatments, prescriptions, self-care, and management of additional chronic conditions, is critical to successful dialysis. Without supplemental insurance, out-of-pocket dialysis care costs can be very high for patients. The increased patient experience may lead to missed treatments, unfilled prescriptions, and unmanaged chronic conditions, resulting in overall diminished patient outcomes.

Beneficiaries were asked a series of questions related to costs of dialysis care. This section covers out-of-pocket costs not covered by the ESRD Medicare program.

#### Additional Health Insurance Coverage

Of the 45.5 percent of beneficiaries without Medicaid, about 39 percent reported having additional health insurance coverage. Table 3.44 provides the percentage of beneficiaries who reported having additional insurance coverage.

**Table 3.44: Insurance Other Than Medicare and Medicaid**

Other Type of Insurance*	Percent Beneficiaries
All beneficiaries	61.4
Medigap or Medicare supplement	39.5
Medicare Special Needs Plan	9.7
Medicare Advantage	7.6
Former employer/spouse's employer	22.1
VA insurance	3.9
Purchased insurance	18.6
Additional types	10.2

\*Beneficiaries could indicate insurance through more than one source. As a result, the table does not add to 100%.

## ***Prescription Drug Coverage***

Slightly over 90 percent of beneficiaries reported some type of prescription drug coverage (Table 3.45). Of the beneficiaries reporting prescription coverage, 74.3 percent had Medicare Part D coverage and 42.3 percent reported coverage through Medicaid. About 18 percent indicated that they received a low-income subsidy for purchasing prescription drugs, and about 25 percent reported that they had some other private prescription drug plan.

**Table 3.45: Prescription Drug Coverage**

Type of Prescription Drug Coverage*	Percent Beneficiaries
All beneficiaries	90.2
Medicare Part D	74.3
Medicaid	42.3
Low-income subsidy	18.2
Other drug plan	25.6

\*Beneficiaries could indicate coverage through more than one source. As a result, the table does not add to 100%.

## ***Beneficiary Experience of Cost***

Since out-of-pocket costs may have changed with the implementation of the PPS, CMS was interested in assessing beneficiary concern regarding the cost of dialysis care. More than one-third of beneficiaries reported that they worried about the cost of dialysis (Table 3.46).

**Table 3.46: Cost of Dialysis Care**

Cost of Dialysis Care	Percent Beneficiaries Reporting “Yes”
Worried or concerned about the cost of your dialysis treatments, tests, or prescription medicines	39.3
Kidney doctors or care team talk about the cost of your dialysis treatments, tests, or prescription medicines	17.1

Dual eligibility was the only significant predictor of whether a beneficiary reported concern with dialysis care costs (Table 3.47). Beneficiaries who were *not* dually eligible expressed the greater level of concern, with 44.2 percent of those not receiving Medicaid benefits worried about costs of treatment, compared with 35.2 percent of those receiving Medicaid benefits.

Treatment location was also significantly related to cost discussions with kidney care providers. About 28 percent of beneficiaries dialyzing at home reported discussing cost concerns with their providers, versus 16.1 percent of beneficiaries dialyzing at a facility.

**Table 3.47: Cost of Dialysis Care, by Selected Beneficiary Characteristics**

Beneficiary Characteristics	Percent Beneficiaries Reporting “Yes”	
	Worried or Concerned About the Cost of Your Dialysis Treatments, Tests, or Prescription Medicines	Kidney Doctors or Care Team Talk About the Cost of Your Dialysis Treatments, Tests, or Prescription Medicines
All beneficiaries	39.3	17.1
Race/ethnicity		
White, non-Hispanic	41.8	16.4
Non-White or Hispanic	38.1	17.2
Gender		
Male	37.5	16.6
Female	41.3	17.6
Age		
20-64 years	39.7	<b>18.4*</b>
65 years and older	38.6	<b>14.9*</b>
Education		
Some college or more	38.5	19.0
High school degree or less	40.2	16.1
Dual eligible status		
Yes	<b>35.2*</b>	15.7
No	<b>44.2*</b>	18.8
Facility location		
Urban	39.8	17.1
Rural	37.0	17.1
Facility ownership		
Non-profit	35.2	15.7
For-profit	39.9	17.4
Treatment location		
At-home	41.9	<b>28.3*</b>
Facility based	39.1	<b>16.1*</b>
Self-reported physical health status		
Good or better	<b>32.7*</b>	18.3
Fair or worse	<b>47.5*</b>	15.4

\* $p \leq .05$ .

Policy makers often look at the volume of patients who put off health care as a possible marker of cost burden. Slightly less than 8 percent of beneficiaries said they delayed or did not receive dialysis treatments, tests, or prescribed medicines in the past 3 months (Table 3.48). Of the beneficiaries who delayed or did not complete dialysis care, 45 percent reported cost or lack of insurance as the reason.

**Table 3.48: Delaying Dialysis Care and Cost**

Delaying Care and Cost	Percent Beneficiaries Reporting “Yes”
Delay or not get dialysis treatments, tests, or medicines prescribed	7.6
Lack of insurance a reason for delay*	45.0

\*Denominator excludes those who did not delay care.

Younger beneficiaries ages 20-64, were more likely to report delaying or not completing treatment (9.4 percent) than older beneficiaries ages 65 and older, (4.6 percent). In addition, 9.9 percent of beneficiaries with some college reported delaying treatment, compared with 6.4 percent of beneficiaries with high school education or less. Beneficiaries receiving dialysis at home were more likely to delay or not obtain treatment (13.2 percent) compared to those in-facility (7.1 percent). Small differences occurred in delaying or not obtaining treatment by gender and self-reported physical health status.

Patients who were not Medicaid eligible were significantly more likely to report that they delayed or did not complete dialysis treatments, tests, or prescribed medicines in the past 3 months due to cost or lack of insurance. Approximately 66 percent of non-dual-eligible beneficiaries reported delaying care, versus 30.6 percent of dual-eligible beneficiaries (Table 3.49).

**Table 3.49: Delaying Dialysis Care and Cost,  
by Selected Beneficiary Characteristics**

Beneficiary Characteristics	Percent Beneficiaries Reporting “Yes”	
	Delayed or Not Received Dialysis Treatments, Tests, or Medicines Prescribed	Lack of Insurance a Reason for Delay **
All beneficiaries	7.6	45.0
Race/ethnicity		
White, non-Hispanic	7.7	46.5
Non-White or Hispanic	7.5	45.2
Gender		
Male	8.8*	48.0
Female	6.3*	40.7
Age		
20-64 years	9.4*	46.8
65 or more	4.6*	39.4
Education		
Some college or more	9.9*	55.4
High school degree or less	6.4*	39.0
Dual eligible status		
Yes	7.8	30.6*
No	7.4	65.9*
Facility location		
Urban	7.5	47.6
Rural	8.2	33.4
Facility ownership		
Non-profit	7.1	41.6
For-profit	7.7	45.3
Treatment location		
At-home	13.2*	63.1
In-facility	7.1*	42.4
Self-reported physical health status		
Good or better	6.0*	42.9
Fair or worse	9.7*	46.8

\* $p \leq .05$ .

\*\*Denominator excludes those who did not delay care.

## 3.2 Stakeholder Interviews

This section presents the results from the 30 in-depth stakeholder interviews. These qualitative results are organized according to the following themes:

- initial comments on how stakeholders believe the PPS/QIP has impacted patients;
- stakeholder views of the impact of PPS/QIP on access to care;
- stakeholder views of the impact of PPS/QIP on patient experience of care and daily life;
- stakeholder views of the impact of PPS/QIP on patient choice and education;
- stakeholder views of the impact of PPS/QIP on health outcomes;
- stakeholder views of the impact of PPS/QIP on patient and provider costs; and
- stakeholder views regarding implementation issues with PPS/QIP.

These themes are supported by summaries of the stakeholders' responses with illustrative quotations from the interviews.

### **3.2.1 Initial Comments on How Stakeholders Believe the PPS/QIP Has Impacted Patients**

After obtaining background information on the respondent's organization, and before addressing the specific items of interest for the interviews, we asked respondents to tell us, in their own words, how the PPS/QIP impacted patients. These responses may reflect stakeholders' most salient observations and beliefs regarding the new program.

Respondents provided a wide variety of answers to this initial question. Several people said that the new program had essentially no impact on patients. For example:

*"I think in our population it hasn't had much of an impact ... we have a fairly sophisticated patient population, and we are fairly intensely monitoring our patients with both nurse practitioners and clinicians, though we have seen an increase in the blood transfusions that we have had to use. In terms of the other parameters, it hasn't had much of an impact."*

*"I don't think it does. I think we've always provided certain services and a certain level of quality. I think that we just continue to do that ... we've always focused on those quality measures."*

*"The feedback that I have received in the field had been that there have not been any earth-shattering changes, in general, for patients."*

Many stakeholders, however, said that the PPS/QIP had an impact on patients. About a third felt the impact was largely positive. These respondents largely noted that patients overall now get better care than they once did, because the new program changed dialysis provider behavior:

*“Well, it has impacted them because it’s changed physician behavior. I think if you ask most patients if they are aware of any great change from 2011, they don’t perceive that ... whatever change has occurred on patients has been subtle, it’s been through the actions of physicians, and nurses and providers. The changes have been slight, but I would say all in all probability positive changes, particularly on the quality side.”*

*“You know, to be honest I haven’t seen any real direct changes, you know, directly to patients. What I’ve seen indirectly is that these new directives have kind of put the fire under the physicians, the nephrologists, and the dialysis company to really provide better services to the patients. I’ve seen kind of an uptick in that in the last several months. They’re more aware of it, we’re talking about it in the care plan meetings, you know, in the IT meetings, even in our team meetings, there’s more discussion of it, more emphasis on, you know, direct patient care, what the doctors are doing.”*

*“We’ve had to look at our practices. We’ve had to try to identify which of those practices are most important to improve patient outcomes. And I feel like, in that regard, CMS efforts have been somewhat successful.”*

A couple of respondents (both with for-profit dialysis centers) noted that their facilities are now more focused on getting patients into home dialysis therapy, and that this is ultimately a positive thing for patients:

*“There’s been a definite push towards home therapies, and I think that is very empowering for patients, helps them lead a much more normal and independent life.”*

*“We’re learning a lot of things, and we’re trying to improve processes to be able to ... help our physicians in being able to determine which patients are good candidates for home therapies, and which and what type of support and education need to be reinforced when they go home. So the bundle [has] given life to some of the initiatives that we’ve already started, even before the bundle, but are now geared towards doing well in this PPS environment.”*

One additional positive impact, mentioned by a couple of respondents, is that patients can see how well their dialysis facility ranks with respect to quality (QIP) measures:

*“I think that they’re pleased when they see the postings of how we’re meeting or exceeding the target goals that we’re being asked for clinical outcomes.”*



*“The QIP, as I understand it, we are required to post in our lobby, and it compares us nationwide to other dialysis providers in terms of our quality and as far as I know, we compare favorably nationwide. So I would guess from the patient’s perspective that it gives them some measuring tool to look at our organization and say that we’re a high-quality dialysis provider, and it would tend to increase their confidence in us as a provider.”*

However, at least a third of respondents said that the PPS/QIP had negative implications for patients, in a variety of ways. A few noted that it resulted in providers spending less time with patients, partly because of the additional documentation burdens the program placed upon them, and also because facility managers are under pressure to minimize costs:

*“I think that these initiatives have really increased the burden of documentation for us in a way that, in some ways, takes away a little bit from patient care because we are so under the gun for making sure that everything is documented more extensively than it has been in the past.”*

*“The amount of work that staff need to do has increased, and it’s possible that part of the documentation required by the bundle may have taken away some patient care time. Now whether the patients notice or are impacted directly by this, these changes, is not entirely clear at this point.”*

*“The QIP/PPS has caused my for-profit company to look for ways to reduce costs. And one of the largest ways that they’ve tried to reduce costs is by spreading staff thinner. So dieticians and social workers, and in some cases technicians and nurses, are now covering a larger case load.”*

At least three respondents made a related point—that the new program, while perhaps improving the medical outcomes of dialysis patients in the aggregate, resulted in less individualized patient care, and this may negatively impact certain patients. One respondent felt very strongly about this, offering several examples. He noted that fistulas are not a wise option for every patient, as some have very weak veins that cannot support a fistula. He also noted that some patients are now receiving more dialysis than necessary in order to meet the minimum Kt/V value (a measure of dialysis treatment adequacy) of 1.2, and this negatively impacts their quality of life:

*“There’s no evidence whatsoever that going even higher and higher is better for patients. So if you look at what a patient perceives to be a quality outcome, if you ask them do you feel better at a [Kt/V] of 1.0, or 1.2, or 1.4, they absolutely cannot tell you that they feel better or worse, from a quality of life aspect they don’t see or feel that. But if you ask them would you rather spend four hours in a dialysis unit, or four and a half hours, now you have a big, a big quality of life issue.... So that’s just one unintended consequence of driving therapy for all patients.”*

Another negative impact on patients (in the view of some respondents) concerns medications that are not covered by the bundled payment. A couple of stakeholders noted that patients now find it more difficult (at least on a cost basis) to get EMLA cream, a numbing agent that relieves pain from injections. As one person put it:

*“That’s a big one ... that was pretty upsetting to a lot of patients.”*

A few respondents noted that they are giving patients more iron than before the PPS/QIP, and one of them expressed concern about the potential long-term health consequences:

*“I’ll tell you, I have a little bit of anxiety, because I am not so sure what this long-term intense iron administration is going to cause in these patients five years down the road.”*

A couple of respondents (both with for-profit dialysis centers) mentioned that the PPS/QIP resulted in their organizations putting even more emphasis on attracting patients with private insurance rather than Medicare, since these patients pay at much higher rates:

*“Because the Medicare patients now come with a risk of reduced reimbursement, it’s increased the value to a for-profit industry of the commercial patients, which typically pay like two to four times higher than the Medicare rate. And that’s without any QIP.”*

One of these respondents noted that she sees a two-tiered system developing, in which patients with private insurance get “the VIP treatment.” These patients will have greater contact with a social worker, more success in getting their preferred appointment times, and so on.

Finally, it should be noted that several respondents responded to this initial question by complaining that the QIP measures were not chosen wisely, or that the proposed cut in the bundle payment for 2014 was too drastic. We have not summarized these comments here, since (a) we do not consider them directly relevant to the question asked, and (b) CMS likely received such complaints through the public comment process.

### **3.2.2 Stakeholder Views of the Impact of PPS/QIP on Access to Care**

We asked stakeholders to tell us how the PPS/QIP impacted how patients get care, such as where, how often, and for how long they get care. We probed by asking whether this differed for certain populations (i.e., minorities, elderly, noninsured, undocumented, persons with mental health comorbidities, and home dialysis beneficiaries). We also probed by asking whether any beneficiaries who would have received care under the previous system were denied care under the new system, and if any “cherry picking” of ESRD patients was occurring. Finally, we asked how the new program affected patient access to medications, laboratory tests, and supplies.

About two-thirds of the stakeholders said that the PPS/QIP had no real impact on access to care for ESRD patients, and no differential impact across subpopulations. Although some

respondents noted that the new system resulted in cost pressures and increased the emphasis on attracting patients with private insurance, virtually no one indicated that beneficiary access to care was curtailed in a significant way:

*“I truly don’t see that it has impacted their access to care.”*

*“We accept all patients, and the change in reimbursement structure has not had any impact on how we care for our patients.”*

*“We’ve always taken virtually anyone, and we tend to take patients that are in need, even if we don’t have assurance that everything is covered, because of the not-for-profit status. So for us, it hasn’t made a big change.”*

*“There’s really nothing that I see in the QIP or in the bundling that affects access to care. I may be wrong but that’s what I think.”*

*“While it’s made the commercial patients more valuable, the Medicare patients are still the bulk of our patients and, you know, you need those to cover the overhead costs of the clinic.”*

Several stakeholders said that the new reimbursement system encouraged dialysis facilities to place more emphasis on home dialysis. They noted that this option is less costly for facilities, and the new system provides incentives to get more of their patients into home-based therapies:

*“I think the one major impact that it’s had is that all facilities and providers are promoting home dialysis more, and I think we’ve seen a growth in peritoneal dialysis in particular, for a lot of reasons. In part it’s financial.”*

*“I think we’ve certainly seen providers paying closer attention to home dialysis. There are some incentives for getting patients home, and the cost of care for home dialysis is more efficient. So we’ve seen an increase, at least a small increase I think, in the growth of home dialysis programs.”*

One stakeholder representing an association suggested that access was curtailed to some degree, due to some facilities cutting back on evening hours:

*“I have heard talk about some of our facilities deleting their evening hour shift because of labor cost. And so now our patients that work are having difficulty finding times to dialyze either before or after work.”*

Most stakeholders expressed no awareness of dialysis facilities “cherry picking” the healthiest ESRD patients, whose care is less costly. As one put it:

*“I don’t believe that the cherry picking and those kinds of things that were talked about early on have occurred. I haven’t seen it when I talk to my other colleagues or chief medical officers.... No one has sensed that that’s occurring.”*

A stakeholder representing a hospital that apparently anticipated cherry picking as a potential problem told us of how they have taken a strict line with the facilities in their community in order to prevent it:

*“We have not had push-back from the dialysis units in terms of uninsured patients or undocumented patients. As a matter of fact, we have taken a pretty strong line that we would not send them anybody if they gave us a hard time about any single patient, so the physician group [has] been pretty adamant, and the truth is we have had no problem.”*

Representing a minority, it is of note that several stakeholders believe that cherry picking of ESRD beneficiaries is happening. Not surprisingly, no one we interviewed admitted that their facility is cherry picking, but several stakeholders said they heard anecdotal reports of it happening elsewhere, including at other facilities in their communities. One respondent told us that a group of nephrologists in her town recently opened their own dialysis facility and that they are accepting only the healthiest patients. Another person (a corporate executive for a large dialysis organization) noted that he received anecdotal reports that in some areas of the country his facilities are seeing an increase in problem patients—those who are noncompliant or very sick, making it harder to reach quality goals. Because this organization is so big, his facilities can take everyone, but he suspects that in those areas of the country some competing facilities may be cherry picking patients. As others put it:

*“There are certainly ... some facilities who were doing that. Our company has tried to come down on it very hard and tell people that it’s not OK to do that. ... But where I work, truly, we have not done that. So I do know that it has gone on for some people. It has not gone on for us. We take in all.”*

*“I do hear anecdotal stories that that’s happening in some areas of the country ... obviously patients who have commercial insurance rather than a Medicare program are going to be highly desired. And then Medicare beneficiaries who have a lot of comorbid conditions if there is an opportunity for a provider to not accept them, I think that is happening from time to time. But I can’t give you any facts.”*

*“There’s rumors. We’re seeing, in people who get referred from ... outside our system, they’re generally tending to be a little bit sicker. You kind of wonder, but can you prove it? No.”*

Several stakeholders, including some who acknowledged that the new program has so far had little or no impact on patient access to care, expressed concern about its future impact. Some of this concern was clearly driven by the anticipated cut in the bundled rate for 2014. A few respondents suggested that some dialysis facilities will not remain viable, especially those in rural and/or low-

income communities, and that further consolidation in the industry is inevitable. Some respondents also predicted that cherry picking of patients will become more common:

*“I can’t say that for sure but ... it’s conceivable that some facilities may not have been able to stay viable with the PPS and in that case, and I don’t have data for this, you understand. I’m just saying that if indeed facilities have lost viability then they ... might be acquired.... It moves provision of resources to larger providers, and there may be access to care lost from the system in that regard.”*

*“If you have very-high-cost patients ... if you have patients who are going to require antibiotics and you don’t have the ability, because you’re losing money, to take risks on these patients, I think that really stands a chance of ... limiting access.”*

*“I’m concerned about the access to care for some of our patients who have multiple comorbidities, where it’s going to take a lot of time and a lot of resources for taking care of that patient ... in fact, I just returned from a meeting where it was brought up again that there will be cherry picking, that the patients who are very stable and do not need to have a lot of interventions will be selected for the facilities. And those patients that require a lot of interventions, nursing care, medications, that, unfortunately, facilities will not be accessible to them.”*

### **Patient Access to Drugs and Biologicals**

We asked stakeholders how the PPS/QIP affected the type, amount, and administration of drugs and biologicals for patients. As part of this discussion, we probed by asking whether there were changes in (a) the use of oral drugs versus injectable equivalents (e.g., for iron and vitamin D), (b) the use of erythropoiesis-stimulating agents (ESAs, including Epogen [epoetin alfa]), (c) the use of antibiotic therapies, and (d) how patients get their drugs.

Although a few stakeholders said that the new program had no effect on patient access to drugs and similar therapies, most indicated that it had at least a minor impact. Some stakeholders told us that more iron is being used now, since it is inexpensive and allows for lower amounts of ESA use:

*“Once the bundle came along ... everyone took a fresh look at the science and said, OK, can we really get by with less, and if we can get by with less of these drugs, how do we have to alter the protocol? Well, the result was that a whole lot less Epogen was used but a whole lot more iron was used, but iron is a lot less expensive than Epogen.”*

*“We’ve exploited the use, within clinical practice guidelines and safe recommended levels, of using iron instead of jumping to an increased EPO [erythropoetin] dose, You could give thousands upon thousands of dollars of*

*Epogen, or an ESA, and if you're not iron repleted, it's not going to work, so ... we've gotten much more diligent about using iron, so that we can achieve the goals we're trying to get with hemoglobin and not exceed them, before just reaching for more EPO."*

It should be noted, though, that some respondents had serious concerns about the potential long-term effects of this increased iron use with ESRD patients:

*"I can't give you hard data, but it is my impression that we're administering a lot more iron. I do know ferritins have increased in the patient population. I don't think our mean hemoglobins have changed a whole lot, but they may have dropped a little bit. I'll tell you, I have a little bit of anxiety because I am not so sure what this long-term intense iron administration is going to cause in these patients five years down the road."*

*"And we don't want to see the hemoglobin ... drop, because then we'll get dinged. But it's an ongoing ginormous experiment, if this large increase in iron will over time have harmful effects. And lately some of the doctors who I respect have been voicing their concern that we need to back off on this propensity to use voluminous amounts of iron. They're worried."*

Many stakeholders noted that ESRD patients are now given lower amounts of ESAs (generally referring to Epogen), compared with a few years ago. Some attributed this change strictly to the FDA black box warning for Epogen, but others said it was at least partly due to the PPS/QIP, and the ensuing need to reduce costs:

*"I think it's certainly reduced some of the medications that they get. I do not see that it has really impacted their quality of care, only because I think our organization has been very cost focused. ... I see them getting lower doses of Epogen. So they're ... maintaining lower hemoglobin counts than we once did. ... So that's where the biggest change that I see is in the medical management of the anemia. At this point, I don't see that it's harmed them but, you know, if further drops were allowed, then it might be an issue."*

Most stakeholders said that the PPS/QIP had no impact at all on the use of antibiotic medications for ESRD patients. A few did mention that their facilities are using less of (or have stopped using) some of the more costly antibiotics. Similarly, most said that the program had no impact on the use of injectable drugs versus their oral equivalents. A few mentioned that they now rely more on an inexpensive oral form of vitamin D, though patients can still receive more expensive vitamin D treatments if recommended by a doctor.

Several stakeholders providing dialysis care told us that the PPS/QIP has made their organizations more “cost aware,” and this has resulted in efforts to be more efficient with regard to drug therapies. As one respondent put it:

*“We’re not sacrificing care, but we’re trying to be more responsible about the efficiency and the efficacy of the meds we use. ... So, instead of ... having to waste a large amount of expensive drug at the higher dosage, we’re trying to use things like the lowest common unit of a med, and then just use more of them, instead of wasting meds.”*

Finally, the PPS/QIP so far had very little impact on how ESRD patients get their medications. Some stakeholders in large dialysis organizations said that they established (or are implementing) their own company pharmacies for ESRD patients—plans for these efforts existed before the PPS/QIP, but the new program accelerated their implementation. One respondent involved in patient care said there is pressure from the corporate level to persuade patients to use the company pharmacy, but noted that most patients prefer to use the pharmacies they used in the past. Another respondent said that at-home dialysis patients previously purchased their oral vitamin D and an injection site numbing cream from their drug store, but now these products are included in the bundle that the company’s mail-order pharmacy provides to patients.

### **Patient Access to Laboratory Tests**

We asked stakeholders if they saw any changes in the frequency of laboratory tests for ESRD patients after PPS/QIP implementation. We also asked if the program resulted in any shifting of responsibility for ESRD laboratory testing to other providers (such as a primary care doctors), and whether the tracking/billing of laboratory tests was affected.

Several stakeholders representing dialysis facilities said they reduced the frequency of some ESRD-related laboratory tests since PPS/QIP implementation.

*“So in terms of lab tests, I know that we had our medical directors go through, and we did change some of the frequencies when they said well ... we don’t need to do this one every month, we could do it quarterly. So I believe there have been some changes in the frequency of lab tests and lab draws.”*

*“There are a lot stricter guidelines on when things can be taken, how often labs can be taken, and so, we’re definitely seeing fewer labs drawn. Is that a bad thing? Yes and no. I mean, sometimes they get labs drawn a lot, and it really it doesn’t impact care.”*

The stakeholder interviews did not reveal any shifting of responsibility for ESRD-related testing to other health care providers, or more than a minor impact on the tracking/billing of ESRD-related tests. However, virtually all of the respondents representing dialysis facilities told us that they

stopped performing laboratory tests that are unrelated to ESRD, which was a very common practice prior to the PPS/QIP, as a courtesy to the patient and other doctors. It seems that the new reimbursement system has largely put an end to this practice, and several respondents noted that this is having a negative impact on patients, who now have to go to multiple places to have blood drawn for testing:

*“I think there’s a lot of concerns under the bundle about ... courtesy labs.... So essentially because patients come to a dialysis unit, we have easy access to the bloodstream. They don’t need to be stuck again to get a blood draw ... which is really more important in dialysis patients because we need their veins to create dialysis access ... and so the more times veins gets stuck, the worse the shape the veins are when you need them for dialysis access, which is important. So if somebody wants to send off whatever labs, I think the facilities are a lot less accommodating of these. And that’s been a bit of a ... negative for patients. Something that was done essentially as a patient service, and it has a little bit of harm, because again you are subjecting someone to more blood sticks when we’re trying to save veins.”*

*“So it changed where the patients get their labs. The dialysis center no longer became sort of the central ‘go to’ place to have labs drawn, since we couldn’t charge for those labs anymore.... I’m certain that this is an inconvenience to patients. I don’t know how it could not be.”*

*“My own personal view is that this is (a) a big inconvenience for the patient and (b) I think it probably ends up costing the system more by doing it that way as well. And it makes it harder to track certain things such as thyroid levels and other issues, anticoagulation levels, such as when the patients are treated with anticoagulants and we want to monitor them on a weekly basis, well that has become a little bit more cumbersome to do.”*

*“There used to be a lot of flexibility ... if one of their primary care [doctors] wanted a lab drawn, we could draw it here. That just does not happen at all anymore, period.... And the drawback from the patient’s perspective is ... they have to get themselves to the lab to get the blood drawn, and transportation is a big problem with them.”*

### **Patient Access to Supplies, Devices, and Durable Medical Equipment**

As a final question related to the topic of access to care, we asked stakeholders if there were any changes to supplies, devices, and durable medical equipment since PPS/QIP implementation. Responses suggested that there was not a major impact on these things. Most stakeholders said they were unaware of any impact, but several did note that they are now more diligent about managing supplies in a more efficient manner so as to avoid waste:



*“Yeah, there used to be less control over the supplies, like Band-Aids and four-by-fours and needles and all that kind of stuff, and there’s a great deal more diligence about that because ... when you have patients walk out with a box or two every time they leave, for their own personal use at home ... that was just an open faucet.”*

*“[The company] just asked us to ... make sure we’re counting our inventory correctly before we order supplies, so we don’t have a wastage of supplies.”*

One stakeholder with an association said that she heard that some facilities may not be upgrading their dialysis machines as often as they did before the PPS/QIP. However, none of the representatives from dialysis facilities reported any delays in upgrading equipment.

### **3.2.3 Stakeholder Views of the Impact of PPS/QIP on Patient Experience of Care and Daily Life**

We asked stakeholders how the PPS/QIP changed patients’ experience in getting dialysis care. We also asked them to discuss how the new program changed daily life for patients.

Most stakeholders indicated that the program had no real impact on patients’ experience of dialysis care, since any changes that facilities made as a result of the program are beyond the awareness of patients. As one put it:

*“I don’t think it’s had a direct impact ... on the patients.... I think it’s more at the ... corporation level, you know, the handling the money and the finances ... being more aware of quality assurance issues, as far as what’s going to affect payment. I think its effect is at that level, it hasn’t maybe had the trickle-down effect ... that the patients are seeing it affecting their care at all. We haven’t really allowed it to ... change the quality of care that we’re giving,”*

There were several exceptions, however. A few stakeholders pointed to longer dialysis times, noting that some patients are annoyed by longer periods of dialysis time:

*“We have kind of moved toward longer treatments for patients, and there are some percentage of patients that don’t want to do those longer treatments.”*

One stakeholder (an association representative in contact with many facilities) noted that some facilities reduced their operating hours, which caused inconvenience for some patients. This respondent also said that some facilities cut back on niceties for patients (e.g., blankets, refreshments). A couple of respondents suggested that issues related to dialysis facility staffing that may be negatively affecting some patients’ experience of care:

*“I think ... it may, it may be a little bit more negative, because I do know that the patients have mentioned the decreased staffing in the facilities, so that is perceived.”*

*“I think there’s maybe a little more stress on the staff, and that always trickles down.”*

One stakeholder said that the CMS requirement to post QIP rankings has a positive effect on the experience of dialysis care:

*“It’s kind of a confidence thing ... the assurance that CMS is there and looking at dialysis organizations and comparing them nationally and holding us to a standard ... the patients like to know that where they’re going is being held to a standard ... that’s what I see with new patients. They notice that.”*

Most of the stakeholders also indicated that the PPS/QIP had no impact on the daily lives of dialysis patients. Several respondents said that they did not have an answer for this question. A couple of respondents argued that increased dialysis times are resulting in a lower quality of life for some patients. Another said that daily life improved for many patients because of lower infection rates due to the new emphasis on replacing catheters with fistulas.

### **3.2.4 Stakeholder Views of the Impact of PPS/QIP on Patient Choice and Education**

Stakeholders were asked to discuss how much choice beneficiaries have regarding treatment modality and medicines, and how this was affected by the PPS/QIP. They were also asked how patient education is handled with respect to self-management and nutrition, and how it differs under the new program.

#### **Patient Choice**

When discussing patient choices, almost all of the respondents focused exclusively on treatment modality, rather than medications (although a couple of dialysis providers noted that their patients can choose whether or not to go on Epogen). And virtually all of these stakeholders noted that patients have a high degree of choice when choosing a modality. Only one person (representing a dialysis provider in a rural setting) indicated that home dialysis is not an option for patients. As for the effect of the PPS/QIP, no one said that it has led to a restriction of choices for patients. Many stakeholders told us that the new program encouraged a push to get more patients into home dialysis options, and that this effort places a greater emphasis on patient choice:

*“I think that there has been, indirectly or partially as a result of bundling proposals ... a lot more education for patients regarding home dialysis, so I think it’s really encouraged patient choice and awareness.”*

*“I think they have more choice because of the push for the home therapies. I think in the past it’s been offered, but it hasn’t been kind of pushed as much, just because, well, once you start on hemo and you’re used to it and so forth ... why make a change? Whereas really in the long run, I think ... peritoneal*

*is a much better form of dialysis, if it's appropriate for the patient. ... And so, I think that's been a good thing."*

But some respondents were very straightforward in noting that cost savings (rather than emphasis on choice) was the primary motivation behind this greater push for home therapies:

*"Yeah well, they're trying to give people more choice, and it definitely has changed where we are pushing, we are pushing like never before home dialysis. And I'd like to tell you we're pushing it because it's proven to be better, in some ways it is better and in other ways it may not be better, depends on the individual patient. But you know what else is driving us to be pushing home dialysis? Well, we make more money on home dialysis patients, it's much lower cost for us."*

### **Patient Education**

With respect to patient education, most stakeholders discussed how it is an ongoing process with all patients, though some noted that it is particularly in-depth when the patient first begins dialysis treatment. Some respondents spoke of free classes on nutrition and so forth that they hold within their clinics. Most stakeholders said that the new PPS/QIP had no impact on patient education. But a few noted otherwise:

*"It has changed, because we make sure that every patient learns all the same information. Before it was just ... sporadic. But now it's ... everybody knows all of the same information, and we're making sure that it's the same time for everyone. So at the start and then annually."*

*"I think that dialysis providers have invested a little bit more in predialysis education because the transition time is an extremely expensive time, both to the health care system as well as to the dialysis facility. If you receive a patient who crashes onto dialysis, they're much more costly than a patient who shows up well-educated, well-prepared, and has a smooth start."*

### **3.2.5 Stakeholder Views of the Impact of PPS/QIP on Health Outcomes**

We asked stakeholders how the PPS/QIP affected health outcomes for beneficiaries. Specifically, we probed for any impact on the following:

- hospitalization rates
- anemia management and blood transfusion rates
- dialysis adequacy
- use of evidence-based protocols
- infection rates and vascular access
- complication rates of dialysis

## **Hospitalization Rates**

Most stakeholders indicated that the new program had no impact on hospitalization rates. Several could not offer an answer (social workers and dietitians were especially likely to say they were unaware of the program's impact on the various health outcomes of interest), but no one said that hospitalization rates have increased since the PPS/QIP was introduced.

## **Anemia Management and Blood Transfusion Rates**

Responses to our probe on this outcome were mixed. Some stakeholders indicated that blood transfusions have increased in the last couple of years, although a couple acknowledged that this was not entirely due to the PPS/QIP (the other factor being the FDA labeling change for ESAs). A slightly smaller portion said that there was no impact on transfusion rates—one noted that transfusions increased immediately after PPS/QIP implementation, but have decreased since then.

## **Dialysis Adequacy**

Responses to this item were quite mixed as well. Some stakeholders said that the PPS/QIP had no impact at all on dialysis adequacy; a couple of respondents noted that the industry was already doing very well on this measure prior to the PPS/QIP. A smaller portion said that the new program resulted in an improvement in dialysis adequacy. At least a couple of respondents said, however, that although adequacy improved for patients overall, it resulted in less individualized care because facilities are now more focused on meeting aggregate benchmarks. One even said that some patients are burdened by spending more time on dialysis than is needed.

## **Use of Evidence-Based Protocols**

Stakeholders predominantly said that the PPS/QIP has had little or no impact on the use of evidence-based protocols. Several indicated that it may have had some effect, but the trend began prior to the new program. In addition, one nephrologist had this comment:

*“So the question itself assumes that we have an evidence base in dialysis care. And I think that’s a bad assumption, because the number of randomized clinical trials to really guide dialysis care that have shown anything you can hang your hat on is zero. So in that sense, it hasn’t done anything to improve evidence-based care. I think even if you look at the URR [urea reduction ratio], there’s no data for that. There’s extensive disagreement about the hemoglobin cutoffs ... basically we’re in an era where you want to be able to quantify things and grade things out, but unless you have the background data to know what is truly good, you can’t do that. But yet we’re still trying to do that. And that’s the catch-22 here.”*

## ***Infection Rates and Vascular Access***

Responses to this item were mixed among the stakeholders. The most frequent response was that the new program's focus on increasing the use of fistula vascular access had no impact on infection rates. Several respondents said that it lowered infection rates, but some noted that the move away from vascular access through catheters was evident prior to the PPS/QIP. Several said that they do not know whether or not there was any impact, with a couple of stakeholders noting that it was too early to tell. A couple of respondents also complained that the program focused on fistulas, while ignoring the use of grafts as an option for vascular access.

## ***Complication Rates of Dialysis***

Stakeholders largely said that the new PPS/QIP had no impact on dialysis complication rates. A couple of respondents suggested that this will likely be an issue in the future, however, due to nurses' burden with new program documentation requirements that take time away from patient care.

### ***3.2.6 Stakeholder Views of the Impact of PPS/QIP on Patient and Provider Costs***

Stakeholders were asked how the cost of care to patients changed since the PPS/QIP was introduced. We probed by asking whether costs have shifted to patients through higher copayments or other fees. Stakeholders were asked how costs to providers have been affected by the PPS/QIP, and probed by asking whether costs are being shifted to others, such as hospital emergency departments, Medicaid, or other agencies.

About two-thirds of the stakeholders replied that the PPS/QIP had no impact on ESRD patients' out-of-pocket costs for care. It should be noted that several of these stakeholders qualified their answer by saying that they did not have direct knowledge of this issue. Instead, they assumed the new program had no impact on patients' costs because they had not heard otherwise (e.g., complaints from patients). Some stakeholders said that the bundle increased patients' costs, however. They pointed out that patients now pay for certain medications that are not covered by the bundle and that used to be provided by their dialysis facility. They also suggested that Medicare beneficiaries without secondary coverage for their 20 percent coinsurance are now paying more out of pocket. But no one said that ESRD patients are paying higher copayments for their treatments.

As for the impact of the new program on the costs to providers of ESRD care, responses were mixed. Several stakeholders (commonly front-line providers) said that they do not know what impact it had. One respondent with a research organization indicated that the cost of care decreased because providers are now using much less Epogen, a very expensive medication. But several other stakeholders said that costs increased for providers. Some noted that this is because the bundle covers some things (e.g., certain medications) that dialysis centers did not provide previously:

*“I think that the direct cost to the providers has increased because of having to take over paying for the drugs that we have. As far as cost to meet some of the QIP, the cost has gone up, for instance we ... have always had a fairly significant population of more than three-times-a-week dialysis, which is more costly. And one of the things that we’ve done is extended our [dialysis times] so we have treatment times that are longer than what we had in the past, and I think there’s one ... unintended consequence of what was done in bundling.”*

Another respondent pointed to the cost of data input into CROWNWeb (a Web-based data collection system for dialysis facilities) as an “unfunded mandate” that facilities had to absorb. A few stakeholders suggested that some facilities are shifting costs to hospitals by referring patients who need blood transfusions to those settings, whereas before the PPS/QIP these facilities may have performed the transfusions themselves. A couple of respondents noted that many dialysis facilities are no longer doing “courtesy lab draws” (blood being drawn for tests unrelated to ESRD) for other providers, so this is another way in which costs have been shifted other others. But most stakeholders indicated that costs have not shifted in any way. Instead, dialysis centers are absorbing the costs or cutting costs in other ways, and that it is making things quite difficult for some:

*“Fewer people doing more, with less.... Hours have been cut for social workers and dieticians. Nurses have not been replaced, techs have not been replaced. Oh yeah, it’s happening as we speak.”*

*“We’re scrambling to figure out ... how we continue to provide the level of care that we always have, and have been proud to provide, and still stay afloat.”*

### **3.2.7 Stakeholder Views Regarding Implementation Issues With PPS/QIP**

We asked stakeholders two questions related to PPS/QIP implementation. We asked them whether the new program changed the way dialysis organizations bill or process claims, and whether it changed the way dialysis facilities are staffed.

Many stakeholders said that they have no role in billing and claims procedures, and so could not say whether the PPS/QIP affected these processes. Several said that the new program had no impact on how billing and claims are handled. But several others indicated that it has, mainly due to the need for additional documentation of ESRD-related information, and other requirements stemming from the PPS/QIP. As one person (who consults with dialysis organizations) put it:

*“It was a big deal for companies, because they had to totally change their billing systems, and their computer systems to do this ... and it includes the quality outcomes, and so we have to reach these quality outcomes or we’re going to lose this much money. So the billing systems all have to record the QIP outcomes.”*

Another stakeholder, an executive with a large dialysis provider, had this to say:

*“There has been a lot of resources allocated to reengineering billing systems. In addition, there’s been other requirements that were not historically part of the billing system. For example, case mix adjusters are an item within the PPS which are to be documented, and that documentation requires us to go out to the original source of diagnosis, get that document, house that document, put those codes related to that condition onto the claim form. That component of the billing system is a good example of something that is amazingly costly and difficult to do .... a hospital [is] generally where these diagnoses are made. For us to be able to get those other providers to cooperate and provide us with paperwork has been amazingly challenging and expensive and very ineffective. Their health care providers do not have an electronic way to share data, so that generally means a paper copy of a discharge summary, which hospitals are just unwilling to go to the expense of doing. So there’s a component of this PPS that is broken.”*

Similarly, a front-line provider (a nurse) in a dialysis center said this:

*“It was something that within the facility level you were never aware of. But now ... you’re very aware to make sure every order has an ICD-9 code, so when you’re sending your treatment record to, you know, your billing department, your corporate side, if there’s not an ICD-9 code for it, we can’t bill for it. ... So you’re very aware and you make sure you have ICD-9 codes on everything.”*

Most stakeholders told us that the PPS/QIP had no impact at all on how dialysis facilities are staffed. A few stakeholders noted that additional staff was added only at the corporate level to deal with issues related to the PPS/QIP. In addition, a few respondents said that because of cost pressures, their dialysis facilities are limiting staff hours (especially those of dietitians and social workers) and/or letting open positions go unfilled. For example, one social worker complained that she is now expected to take on more patients than was true a few years ago, and has less time with new patients:

*“Well I guess I used to be able to spend a significant time with new patients, and we would sit chair-side and go over educational material. Now, now I am less available to do that with new patients.”*

### **3.2.8 Conclusions**

A wide range of views were expressed across the 30 stakeholder interviews. While there was not consensus across all respondents about the consequences of the PPS and QIP, a few key themes were expressed including the impact of cost-cutting efforts, the importance of patient education, changes in dialysis delivery, and changes to meet reporting requirements. Efforts to cut costs in some dialysis facilities were reported to result in shortened facility hours and less access to some staff, including social workers and dietitians. Both of these were clearly noted as barriers to positive patient experience and quality of life. Additionally, stakeholders noted that lab tests required to

support patient care—but not directly related to dialysis services—were not being offered due to cost, causing patients to have to seek care across a greater number of health care sources.

Not all consequences noted were negative, however. Many stakeholders suggested that greater emphasis was being put on patient education, to ensure a smooth start to dialysis for new patients, and on ongoing education for existing patients. While education initiatives may stem from the need to manage costs, patients certainly benefited from this change. Other new and focused initiatives included greater discussion with patients about dialysis modalities, including home dialysis. Again, while home dialysis is less costly for facilities, many stakeholders agreed that for the right patients, home dialysis offered improved quality of life.

A final set of consequences stemmed from the new reporting requirements—both the clinical measures as well as the reporting itself. To meet QIP standards, some stakeholders reported that patients were being encouraged to undergo longer dialysis treatments. It was unclear to some whether the longer treatments resulted in a measurable health improvement for patients, or just better clinical outcome metrics. Regarding the reporting itself, a few stakeholders noted the burden associated with the additional reporting requirements, and suggested that these required anything from a systems overhaul to more staff time to accomplish the needed reporting.

On the whole, stakeholders did not report overwhelmingly negative consequences for patients as a result of the PPS and QIP. Rather, a mix of changes resulted, many of which benefited patients, while others required dialysis facilities and systems to more carefully monitor care delivery and system structure. In light of the further changes in 2014, many stakeholders were carefully monitoring the situation to assess future impact on delivery of care to ESRD patients.



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## APPENDIX A: DETAILED EXPLANATION OF WEIGHTING PROCEDURE

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This appendix provides a detailed description of the determination of the unconditional sampling probability and base weight. This is a follow-on description intended to supplement the information on weighting provided in Chapter 2.

The final sample used by Westat's Telephone Research Center was composed of two samples selected at different time points. The first (original) sample included 8,750 beneficiaries and an additional sample included 800.

The total sample that was fielded consists of the original sample of 8,750 (denoted by  $S_1$ ) and the fielded additional sample of 800 (denoted by  $S_{2a|1}$ ), totaling the sample size of 9,550. Let this total fielded sample be denoted by  $S$ . So,  $S = S_1 \cup S_{2a|1}$ . We will use  $S_{2|1}$  to denote the full additional sample of 6,750. Note that the additional sample was selected from the sample frame after removing the original sample, and thus, it is conditional on the original sample, which is indicated by “|1” in the subscript.

In the following, we explain how we determined the unconditional selection probability that a unit (denoted by  $u$ ) is selected in the total fielded sample of  $S$  regardless when it was selected (in the original sample or in the additional sample).

The unconditional selection probability  $P_u$  is given by

$$P_u = P(u \in S) = P(u \in S_1 \cup S_{2a|1}) = P(u \in S_1) + P(u \in S_{2a|1}),$$

where  $P$  is used as the probability function, and  $P(u \in S)$  denotes the probability that  $u$  is selected in  $S$ . It is clear that a unit can be selected in the fielded additional sample only when it has not been selected in the original sample, and then has been selected in the full additional sample  $S_{2|1}$ . Finally, it has to be subsampled into the fielded additional sample  $S_{2a|1}$ . Therefore, we have,

$$\begin{aligned} P_u &= P(u \in S) = P(u \in S_1) + P(u \in S_{2a|1}) \\ &= P(u \in S_1) + P(u \in \bar{S}_1)P(u \in S_{2a|1}|S_1) \\ &= P(u \in S_1) + P(u \in \bar{S}_1)P(u \in S_{2|1}|S_1)P(u \in S_{2a|1}|S_{2|1}) \\ &= P(u \in S_1) + \{1 - P(u \in S_1)\}P(u \in S_{2|1}|S_1)P(u \in S_{2a|1}|S_{2|1}) \\ &= P_1 + (1 - P_1)P_{2|1}P_{2a|1}, \end{aligned}$$

where  $\bar{S}_1$  is the complement of  $S_1$ , and so if  $u \in \bar{S}_1$ , it means that  $u$  has not been selected in the original sample,  $S_1$ .  $P_1 = P(u \in S_1)$ ,  $P_{2|1} = P(u \in S_{2|1}|S_1)$ , and these probabilities are provided by the SAS SURVEYSELECT procedure, which was used to select the samples.  $P_{2a|1} = P(u \in S_{2a|1}|S_{2|1})$ . These probabilities are presented in Table A-2. The table shows the stratum level sample sizes ( $n_{2|1}$ ) of the full additional sample and those ( $n_{2a|1}$ ) of the fielded additional sample.  $P_{2a}$  in the table is defined as

$$P_{2a} = (1 - P_1)P_{2|1}P_{2a|1}.$$

Since  $S_{2a|1}$  was selected by simple random sampling, we have

$$P_{2a|1} = n_{2a|1}/n_{2|1}.$$

Finally, we have

$$P_u = P_1 + P_{2a}.$$

This unconditional sampling probability is presented in Table A-2. For the sake of convenience in presentation, we will use Alpha-numeric codes to denote the stratum and race/ethnicity groups as follows in Table A-1:

**Table A-1: Alpha-Numeric Code for Stratum and Race/Ethnicity Variables**

Variable	Alpha-Numeric Code <sup>1</sup>	Category
Stratum	1A	Large Dialysis Organization (LDO)
	1B	Small Dialysis Organization (LDO)
	1C	Hospital/Independent
	2	Home-Peritoneal
Race/Ethnicity	0	Unknown race/ethnicity
	1	Non-Hispanic White
	2	Non-Hispanic Black
	3	Non-Hispanic Other races
	5	Hispanic, all races

<sup>1</sup>These codes are also used in the sample data file.

Note that the probabilities,  $P_1$  and  $P_{2|1}$ , depend on the race/ethnicity within stratum since beneficiaries of Hispanic origin (Race/Ethnicity category 5) and Other race (Race/Ethnicity category 3) were given twice as large probability as that for the other races, White (Race/Ethnicity category 1), Black (Race/Ethnicity category 2), and unknown (Race/Ethnicity category 0).

Once the unconditional sampling probability is determined, the base weight for beneficiary  $u$  is then defined by

$$W_u = \frac{1}{P_u},$$

which is shown in Table A-2.

**Table A-2: Unconditional Sampling Probability, Information Needed to Calculate the Probability, and Resulting Base Weight**

Stratum	Race/ Ethnicity	$P_1$	$P_{2 1}$	$n_{2 1}$	$n_{2a 1}$	$P_{2a 1}$	$P_{2a}$	$P_u$	Base Weight
1A	0	0.04002	0.03246	2700	322	0.11926	0.003872	0.04374	22.86
1A	1	0.04002	0.03246	2700	322	0.11926	0.003872	0.04374	22.86
1A	2	0.04002	0.03246	2700	322	0.11926	0.003872	0.04374	22.86
1A	3	0.08004	0.06493	2700	322	0.11926	0.007743	0.08716	11.47
1A	5	0.08004	0.06493	2700	322	0.11926	0.007743	0.08716	11.47
1B	0	0.11017	0.09951	1620	288	0.17778	0.017692	0.12591	7.94
1B	1	0.11017	0.09951	1620	288	0.17778	0.017692	0.12591	7.94
1B	2	0.11017	0.09951	1620	288	0.17778	0.017692	0.12591	7.94
1B	3	0.22035	0.19903	1620	288	0.17778	0.035383	0.24793	4.03
1B	5	0.22035	0.19903	1620	288	0.17778	0.035383	0.24793	4.03
1C	0	0.10592	0.09475	1080	190	0.17593	0.016670	0.12082	8.28
1C	1	0.10592	0.09475	1080	190	0.17593	0.016670	0.12082	8.28
1C	2	0.10592	0.09475	1080	190	0.17593	0.016670	0.12082	8.28
1C	3	0.21183	0.18951	1080	190	0.17593	0.033339	0.23811	4.20
1C	5	0.21183	0.18951	1080	190	0.17593	0.033339	0.23811	4.20
2	0	0.17505	0.16964	1350	0	0	0	0.17505	5.71
2	1	0.17505	0.16964	1350	0	0	0	0.17505	5.71
2	2	0.17505	0.16964	1350	0	0	0	0.17505	5.71
2	3	0.35011	0.33928	1350	0	0	0	0.35011	2.86
2	5	0.35011	0.33928	1350	0	0	0	0.35011	2.86

### ***Imputed Frame Variables and Survey Eligibility and Their Imputation Rates***

To support the weighting processes, 78 variables were imputed. These variables are presented with their imputation rate in Table A-3. For the definition of these variables, see Table A-8 at the end of this appendix.

**Table A-3: Frame Imputed Variables and Their Imputation Rate**

Variable	Imputed Cases	Imputation Rate (%)
ELIGIBILITY	5408	56.63
BENE_RACE_CD	35	0.37
AVG_HEMO	1252	13.11
BSA_40	17	0.18
BSA_41	15	0.16
BSA_42	20	0.21
PROFIT_NON	119	1.25
SCORE_DIAL	70	0.73
HCC1	70	0.73
HCC2	70	0.73
HCC5	70	0.73
HCC7	70	0.73

**Table A-3: Frame Imputed Variables and Their Imputation Rate (continued)**

Variable	Imputed Cases	Imputation Rate (%)
HCC8	70	0.73
HCC9	70	0.73
HCC10	70	0.73
HCC15	70	0.73
HCC16	70	0.73
HCC17	70	0.73
HCC18	70	0.73
HCC19	70	0.73
HCC21	70	0.73
HCC25	70	0.73
HCC26	70	0.73
HCC27	70	0.73
HCC31	70	0.73
HCC32	70	0.73
HCC33	70	0.73
HCC37	70	0.73
HCC38	70	0.73
HCC44	70	0.73
HCC45	70	0.73
HCC51	70	0.73
HCC52	70	0.73
HCC54	70	0.73
HCC55	70	0.73
HCC67	70	0.73
HCC68	70	0.73
HCC69	70	0.73
HCC70	70	0.73
HCC71	70	0.73
HCC72	70	0.73
HCC73	70	0.73
HCC74	70	0.73
HCC75	70	0.73
HCC77	70	0.73
HCC78	70	0.73
HCC79	70	0.73
HCC80	70	0.73
HCC81	70	0.73
HCC82	70	0.73
HCC83	70	0.73

**Table A-3: Frame Imputed Variables and Their Imputation Rate (continued)**

Variable	Imputed Cases	Imputation Rate (%)
HCC92	70	0.73
HCC95	70	0.73
HCC96	70	0.73
HCC100	70	0.73
HCC101	70	0.73
HCC104	70	0.73
HCC105	70	0.73
HCC107	70	0.73
HCC108	70	0.73
HCC111	70	0.73
HCC112	70	0.73
HCC119	70	0.73
HCC130	70	0.73
HCC131	70	0.73
HCC132	70	0.73
HCC148	70	0.73
HCC149	70	0.73
HCC150	70	0.73
HCC154	70	0.73
HCC155	70	0.73
HCC157	70	0.73
HCC158	70	0.73
HCC161	70	0.73
HCC164	70	0.73
HCC174	70	0.73
HCC176	70	0.73
HCC177	70	0.73

### ***Control Totals Used in the Raking Procedure***

A two-dimensional raking procedure was used to make the raking adjusted weights conform to the known (adjusted) frame total counts, which are shown in along with the original counts (before adjustment) in Tables A-4 and A-5.

**Table A-4: Control Totals for the First Raking Dimension**

STRATUM	GENDER	RACE/ETHNICITY	ORIGINAL COUNT	ADJUSTED COUNT
1A	1	0	154	NA
1A	1	1	16168	16228
1A	1	2	19449	19522
1A	1	3	2514	2523
1A	1	5	3079	3091
1A	2	0	108	NA
1A	2	1	13608	13649
1A	2	2	17780	17833
1A	2	3	2225	2232
1A	2	5	2277	2284
1B	1	0	48	NA
1B	1	1	3586	3606
1B	1	2	3218	3236
1B	1	3	898	903
1B	1	5	778	783
1B	2	0	31	NA
1B	2	1	3015	3028
1B	2	2	2973	2985
1B	2	3	791	794
1B	2	5	628	631
1C	1	0	31	NA
1C	1	1	2650	2664
1C	1	2	2217	2228
1C	1	3	549	552
1C	1	5	563	566
1C	2	0	26	NA
1C	2	1	2187	2198
1C	2	2	2091	2102
1C	2	3	464	466
1C	2	5	432	434
2	1	0	27	NA
2	1	1	2523	2539

**Table A-4: Control Totals for the First Raking Dimension (continued)**

STRATUM	GENDER	RACE/ETHNICITY	ORIGINAL COUNT	ADJUSTED COUNT
2	1	2	1189	1196
2	1	3	375	377
2	1	5	291	293
2	2	0	31	NA
2	2	1	2191	2207
2	2	2	1418	1428
2	2	3	342	345
2	2	5	301	303

**Table A-5: Control Totals for the Second Raking Dimension**

AGE_GRP	RURAL	PROFIT_NON	ORIGINAL COUNT	ADJUSTED COUNT
1	0	Missing	104	NA
1	0	0	13915	14008
1	0	1	1668	1679
1		Missing	23	NA
1	1	0	2639	2660
1	1	1	272	274
2		Missing	273	NA
2	0	0	38159	38404
2	0	1	4310	4338
2		Missing	96	NA
2	1	0	7162	7248
2	1	1	845	855
3		Missing	151	NA
3	0	0	18940	19076
3	0	1	2060	2075
3		Missing	57	NA
3	1	0	3813	3863
3	1	1	493	500
4		Missing	150	NA
4	0	0	13550	13685
4	0	1	1510	1525
4		Missing	48	NA
4	1	0	2624	2666
4	1	1	364	370



## Variables and Terms Used in the Final Model for Nonresponse Weighting Adjustment

The propensity score modeling for nonresponse adjustment first identified 42 most significant variables as shown along with its significance level in Table A-6. The main and interaction terms (244) remained in the final model are presented in Table A-7 using the V-names (defined in Table A-6).

**Table A-6: Significant Main Effect Variables**

Order of Significance	V-name	Variable Name	Significance Level	Description
1	v1	DUAL	$\leq .0001$	Identifies the beneficiary's dual-eligible status: 1=dual-eligible, 0=non-dual-eligible
2	v2	BENE_RACE_CD2	$\leq .0001$	Imputed variable of BENE_RACE_CD: Identifies the beneficiary's race/ethnicity: 1=white, 2=black, 3=Asian/Native American/other, 5=Hispanic
3	v3	AGE	$\leq .0001$	The age of the beneficiary
4	v4	DIALYSIS_TREATMENT	$\leq .0001$	Identifies beneficiary's dialysis treatment modality: 1= in-facility hemodialysis, 2=peritoneal or home dialysis
5	v5	HCC83	0.0003	HCC for Angina Pectoris/Old Myocardial Infarction
6	v6	HCC2	0.0003	HCC for Septicemia/Shock
7	v7	BSA_41	0.0007	High Body Surface Area (BSA), payment adjustment to ESRD facilities in May 2013
8	v8	PARTD	0.0011	Identifies whether the beneficiary is enrolled in Medicare Part D: 1=yes, 0=no
9	v9	CONT_FFS_ENR_2010	0.0071	Identifies whether the beneficiary was continuously enrolled in 2010: 1=continuously enrolled in Medicare FFS from January 2010-December 2010, 0=not continuously enrolled
10	v10	BENE_SEX_IDENT_CD	0.0097	Identifies the beneficiary's sex: 1=male, 2=female
11	v11	ANEMIA_TREATMENT	0.0153	Identifies the beneficiary's anemia management treatment: 1=ESA and IV iron, 2=ESA only, 3=IV iron only, 4= no anemia treatment
12	v12	HCC119	0.0181	HCC for Proliferative Diabetic Retinopathy and Vitreous Hemorrhage
13	v15	NUM_TRANSFUSION	0.0267	Number of days that a beneficiary received a transfusion in the past 3 months
14	v13	HCC130	0.0384	HCC for Dialysis Status
15	v17	HCC19	0.0387	HCC for Diabetes without Complication
16	v14	NUM_READMISSION	0.0430	Number of readmissions to a hospital in less than 30 days, in the past 3 months
17	v16	HCC71	0.0449	HCC for Polyneuropathy
18	v19	HCC17	0.0929	HCC for Diabetes with Acute Complications
19	v18	HCC174	0.0935	HCC for Major Organ Transplant Status

**Table A-6: Significant Main Effect Variables (continued)**

Order of Significance	V-name	Variable Name	Significance Level	Description
20	v20	HCC101	0.1489	HCC for Cerebral Palsy and Other Paralytic Syndromes
21	v23	HCC33	0.1512	HCC for Inflammatory Bowel Disease
22	v22	HCC95	0.1519	HCC for Cerebral Hemorrhage
23	v21	AVG_HEMO2	0.1532	Imputed variable of AVG_HEMO: Hemoglobin level recording, average over the past 3 months
24	v24	HCC54	0.1866	HCC for Schizophrenia
25	v25	HCC75	0.1923	HCC for Coma, Brain Compression/Anoxic Damage
26	v31	HCC132	0.1987	HCC for Nephritis
27	v27	HCC81	0.2003	HCC for Acute Myocardial Infarction
28	v26	HCC55	0.2022	HCC for Major Depressive, Bipolar, and Paranoid Disorders
29	v28	EVER_VF	0.2041	Identifies whether the beneficiary had a flu vaccination at any point during the past year
30	v29	HCC96	0.2129	HCC for Ischemic or Unspecified Stroke
31	v30	HCC21	0.2179	HCC for Protein-Calorie Malnutrition
32	v32	HCC80	0.2354	HCC for Congestive Heart Failure
33	v33	HCC149	0.2392	HCC for Chronic Ulcer of Skin, Except Decubitus
34	v34	HCC51	0.2487	HCC for Drug/Alcohol Psychosis
35	v35	EVER_VP	0.2553	Identifies whether the beneficiary had a pneumonia vaccination at any point during the past year
36	v36	BMI_ADJUSTMENT	0.2559	Identifies whether the beneficiary had a low BMI in any month during the past year
37	v37	NUM_FACS_JAN	0.2608	Number of ESRD facilities in January 2011
38	v38	OWNERSHIP	0.2637	Ownership of the beneficiary's ESRD facility (LDO, regional, independent)
39	v40	HCC161	0.2808	HCC for Traumatic Amputation
40	v39	MYELO_SYND	0.2833	Identifies whether the beneficiary has a diagnosis for myelodysplastic syndrome: 1=yes, 0=no
41	v41	HCC25	0.2866	HCC for End-Stage Liver Disease
42	v42	BSA_40	0.2919	Identifies the beneficiary's dual-eligible status: 1=dual-eligible, 0=non-dual-eligible

**Table A-7: Terms (in v-name) Used in the Final Model in the Order of Significance**

Order	Term	Order	Term	Order	Term	Order	Term	Order	Term	Order	Term
1	v10*v2	36	v2*v38	71	v35	106	v12*v5	141	v10*v17	176	v27*v2
2	v10*v16	37	v2	72	v27*v33	107	v6*v4	142	v13*v26	177	v26*v38
3	v16*v37	38	v14*v12	73	v4*v31	108	v14*v24	143	v3*v11	178	v6*v26
4	v37*v12	39	v31*v11	74	v8*v28	109	v6*v32	144	v26*v30	179	v8*v12
5	v37*v32	40	v12*v11	75	v2*v11	110	v21*v2	145	v35*v38	180	v7*v40
6	v1*v3	41	v16*v13	76	v42*v7	111	v4*v29	146	v12*v38	181	v6*v17
7	v14*v4	42	v42*v21	77	v12*v2	112	v35*v33	147	v7*v29	182	v15*v38
8	v37*v17	43	v7*v37	78	v1*v40	113	v32*v24	148	v42*v33	183	v10*v36
9	v3	44	v3*v5	79	v6*v11	114	v8*v24	149	v36*v2	184	v13*v24
10	v37*v21	45	v14*v13	80	v37*v2	115	v17*v9	150	v12*v9	185	v17*v11
11	v10*v35	46	v3*v24	81	v14*v30	116	v42*v5	151	v7*v33	186	v5*v24
12	v16*v42	47	v6*v36	82	v3*v12	117	v31*v2	152	v32*v41	187	v42*v3
13	v32*v9	48	v37	83	v37*v3	118	v3*v38	153	v40*v36	188	v36*v41
14	v37*v24	49	v42*v37	84	v36*v30	119	v8*v26	154	v10*v11	189	v28*v40
15	v1*v2	50	v28*v12	85	v41*v35	120	v36*v11	155	v40*v15	190	v4*v38
16	v10*v27	51	v10*v29	86	v7*v24	121	v41*v15	156	v42*v29	191	v28*v24
17	v16*v27	52	v5	87	v10*v14	122	v7*v5	157	v40*v21	192	v16*v41
18	v42	53	v29*v11	88	v3*v21	123	v16*v21	158	v16*v2	193	v41*v26
19	v35*v5	54	v28*v32	89	v42*v24	124	v40*v17	159	v21*v38	194	v15*v2
20	v37*v11	55	v16*v38	90	v4*v36	125	v33*v38	160	v8*v11	195	v40*v35
21	v3*v2	56	v37*v36	91	v41*v38	126	v31*v5	161	v8*v40	196	v31*v26
22	v16*v26	57	v16*v4	92	v21*v5	127	v6*v38	162	v27*v15	197	v10*v1
23	v16*v7	58	v6*v2	93	v12*v26	128	v16*v11	163	v33*v2	198	v28*v27
24	v4*v40	59	v14*v32	94	v6*v40	129	v7*v28	164	v21*v11	199	v40*v38
25	v42*v38	60	v17*v2	95	v32*v33	130	v21*v35	165	v35*v11	200	v1*v24
26	v21*v36	61	v8*v30	96	v42*v6	131	v10*v40	166	v8*v15	201	v8*v2
27	v40*v2	62	v9	97	v36*v9	132	v9*v38	167	v40*v11	202	v35*v24
28	v3*v13	63	v29*v2	98	v29*v3	133	v26*v2	168	v4*v41	203	v3*v26
29	v32*v27	64	v12*v31	99	v14*v1	134	v28	169	v1*v15	204	v21*v41
30	v1*v30	65	v27*v26	100	v40*v3	135	v38	170	v5*v38	205	v12*v41
31	v11	66	v12*v32	101	v4*v12	136	v41*v17	171	v31*v30	206	v40*v33
32	v10*v6	67	v10*v24	102	v10*v5	137	v16*v17	172	v9*v11	207	v41*v31
33	v4*v17	68	v7	103	v29*v27	138	v42*v28	173	v42*v40		
34	v32*v36	69	v1*v35	104	v7*v6	139	v7*v3	174	v7*v31		
35	v21*v17	70	v40*v32	105	v16*v6	140	v41*v2	175	v30*v9		

## ***Replicate Weighting for Variance Estimation***

To create the jackknife replicates appropriate for the stratified design used for the ESRD survey, we defined variance strata and units. Variance strata were defined to be the same as the design strata, but the variance units were formed by the random group method. The random group method forms more or less equally sized groups (clusters) of sample units randomly within each variance stratum. This technique is a convenient way of reducing the number of replicates while estimating the variance correctly (Wolter, 2007).

To ensure adequate degrees of freedom for each stratum for separate analysis, yet to have not too many replicates overall, we created 30 replicates in each stratum, which in turn, required creation of 30 variance units in each stratum. Therefore, the total number of replicates was 120 for the entire sample. Replicates were set-up for the combined sample of 9,550 at the beginning of the weighting process.

Replicates were created by dropping one variance unit at a time within a variance stratum or equivalently assigning a zero weight to all beneficiaries in the variance unit. The result was one replicate corresponding to each variance unit, and 30 replicates for each of the four variance strata.

When a replicate is created within each (variance) stratum, by dropping one variance unit at a time, the beneficiaries in remaining variance units in the stratum are weighted up by a factor  $n_s/(n_s - 1)$ , where  $n_s$  is the number of variance units in the stratum (Wolter, 2007, Section 4.3.4 and 4.5). In our case,  $n_s = 30$  for all  $s$ .

To define the replicate weight, we first define the replicate weight factor defined for each variance unit. For variance unit  $a'$  in variance stratum  $s'$  when variance unit  $a$  is dropped from variance stratum  $s$ , for  $s'$  and  $s = 1, 2, 3, 4$ ,  $a = 1, 2, \dots, n_s$  and  $a' = 1, 2, \dots, n_{s'}$ , the replicate weight factor is defined as follows:

$$r_{s'a'}^{(R)} = \begin{cases} 1 & \text{if } s' \neq s \\ \frac{n_s}{n_s - 1} = \frac{30}{29} & \text{if } s' = s \text{ and } a' \neq a \\ 0 & \text{if } s' = s \text{ and } a' = a \end{cases}$$

where  $R$  is the serial replicate number assigned to the replicate created by dropping variance unit  $sa$ . The values of 1 through 30 are assigned to the 30 variance units in variance stratum 1, 31 through 60 to those in variance stratum 2, 61 through 90 to those in variance stratum 3, and 91

through to 120 to those variance units in variance stratum 4. Then the  $R$ -th replicate base weight for all beneficiaries in variance unit  $s'a'$  is given by:

$$W_{s'a'}^{(R)} = r_{s'a'}^{(R)} W_{s'a'}$$

where  $W_{s'a'} = W_u$  for  $u \in s'a'$ , which is the base weight defined in the previous section.

As can be seen in the above formula, the replicate weight is defined for all sample beneficiaries. The replicate weight for the replicate corresponding to the dropped variance unit  $sa$  is determined by:

- It is equal to the (full sample) base weight for the beneficiaries not in variance stratum  $s$ , that is,  $s' \neq s$ ;
- It is inflated by the factor of  $n_s / (n_s - 1) = 30 / 29$  for beneficiaries in the variance units other than the dropped one in the variance stratum  $s$ , that is,  $s' = s$  and  $a' \neq a$ ; and
- It is zero for beneficiaries in the dropped variance unit, that is,  $s' = s$  and  $a' = a$ .

The term “full sample” is used to indicate that the weight is “unaffected” by dropping a variance unit, which results in a reduced sample (i.e., the full sample minus units in the dropped variance unit), which is called a replicate sample or simply a replicate). Note that dropping of the variance unit is realized by assigning a weight of zero. In this way, for each beneficiary record,  $u \in s'a'$ , 120 replicate base weights are defined,  $W_{s'a'}^{(1)}, W_{s'a'}^{(2)}, W_{s'a'}^{(3)}, \dots, W_{s'a'}^{(120)}$ .

These replicate base weights are then passed through the raking procedure, where the raking ratio adjustment factor for a beneficiary is applied not only to the full sample base weight but also to the 120 replicate base weights. These adjusted full sample and replicate weights are then further adjusted through the nonresponse adjustment, resulting in the final full sample and replicate weights. We denote the final weights by  $\omega_u$  for the full sample final weight,  $\omega_u^{(R)}$  for the  $R$ -th replicate final weight,  $R = 1, 2, 3, \dots, 120$ .

Once the full sample and replicate final weights are obtained, we can define a replicate estimate of any parameter of interest in the same way as the full sample estimate is computed but using the replicate weights. For example, the mean,  $\mu_y$  of a survey variable  $y$  is estimated by

$$\hat{\mu}_y = \frac{\sum_{u \in S_r} \omega_u y_u}{\sum_{u \in S_r} \omega_u}$$

where  $S_r$  is the respondent sample. Then the  $R$ -th replicate estimate is defined by

$$\hat{\mu}_y^{(R)} = \frac{\sum_{u \in S_r} \omega_u^{(R)} y_u}{\sum_{u \in S_r} \omega_u^{(R)}}$$

There are 120 replicate estimates, from which we compute the variance estimate for  $\hat{\pi}_y$  by

$$v(\hat{\mu}_y) = \sum_{R=1}^{120} \frac{n_s - 1}{n_s} (\hat{\mu}_y^{(R)} - \hat{\mu}_y)^2 = \sum_{R=1}^{120} \frac{29}{30} (\hat{\mu}_y^{(R)} - \hat{\mu}_y)^2$$

The factor  $(n_s - 1)/n_s = 29/30$  is called the jackknife factor, which should be provided when the jackknife method is used in computer packages such as WesVar and SAS.

This variance estimator is known to be consistent (i.e., it gives a correct estimate when the sample size is large (Shao and Tu, 1995).

If the sampling fraction was not negligible, the finite population correction factor in the above formula should have been applied, but because the sampling fraction was negligible, it was ignored. This makes the variance estimator slightly positively biased but a slight overestimation of the variance was deemed acceptable.

**Table A-8: Frame Variables Used in Weighting**

Variable	Type	Description
Stratum	Char	Identifies sample strata: 1A = hemodialysis, LDO; 1B= hemodialysis, SDO; 1C = hemodialysis, Independent or Hospital-Based; 2 = peritoneal or home dialysis
dialysis_treatment	Char	Identifies beneficiary's dialysis treatment modality: 1= in-facility hemodialysis, 2=peritoneal or home dialysis
age	Num	The age of the beneficiary
bene_sex_ident_cd	Char	Identifies the beneficiary's sex: 1=male, 2=female
bene_race_cd	Char	Identifies the beneficiary's race/ethnicity: 1=white, 2=black, 3=Asian/Native American/other, 5=Hispanic, 0=unknown
DUAL	Char	Identifies the beneficiary's dual-eligible status: 1=dual-eligible, 0=non-dual-eligible
Part D	Char	Identifies whether the beneficiary is enrolled in Medicare Part D: 1=yes, 0=no
anemia_treatment	Char	Identifies the beneficiary's anemia management treatment: 1=ESA and IV iron, 2=ESA only, 3=IV iron only, 4= no anemia treatment
pericarditis	Char	Identifies whether the beneficiary has a diagnosis for pericarditis: 1=yes, 0=no
pneumonia	Char	Identifies whether the beneficiary has a diagnosis for pneumonia: 1=yes, 0=no
gi_bleed	Char	Identifies whether the beneficiary has a diagnosis for GI bleeding with hemorrhage: 1=yes, 0=no
hemo_sickle	Char	Identifies whether the beneficiary has a diagnosis for hemolytic/sickle cell anemias: 1=yes, 0=no
myelo_synd	Char	Identifies whether the beneficiary has a diagnosis for myelodysplastic syndrome: 1=yes, 0=no

**Table A-8: Frame Variables Used in Weighting (continued)**

Variable	Type	Description
monoclonal	Char	Identifies whether the beneficiary has a diagnosis for monoclonal gammopathy: 1=yes, 0=no
NUM_FACS_JAN	Num	Number of ESRD facilities in January 2011
NUM_FACS_Q1	Num	Number of ESRD facilities in first quarter of 2011
OWNERSHIP	Char	Ownership of the beneficiary's ESRD facility (LDO, regional, independent)
PROFIT_NON	Char	Indicates whether the beneficiary's ESRD facility is for-profit or non-profit
RURAL	Num	Indicates whether the beneficiary's ESRD facility is rural: 1=yes, 0=no
CONT_FFS_ENR_2010	Num	Identifies whether the beneficiary was continuously enrolled in 2010: 1=continuously enrolled in Medicare FFS from January 2010-December 2010, 0=not continuously enrolled
num_transfusion	Num	Number of days that a beneficiary received a transfusion in the past 3 months
num_readmission	Num	Number of readmissions to a hospital in less than 30 days, in the past 3 months
avg_hemo	Num	Hemoglobin level recording, average over the past 3 months
BSA_40	Num	High Body Surface Area (BSA), payment adjustment to ESRD facilities in April 2013
BSA_41	Num	High Body Surface Area (BSA), payment adjustment to ESRD facilities in May 2013
BSA_42	Num	High Body Surface Area (BSA), payment adjustment to ESRD facilities in June 2013
BMI_adjustment	Num	Identifies whether the beneficiary had a low BMI in any month during the past year
ever_vh	Num	Identifies whether the beneficiary had a hepatitis b vaccination at any point during the past year
ever_vf	Num	Identifies whether the beneficiary had a flu vaccination at any point during the past year
ever_vp	Num	Identifies whether the beneficiary had a pneumonia vaccination at any point during the past year
ever_hESA	Num	Identifies whether the beneficiary was a high volume ESA user in any month during the past year
SCORE_DIAL	Num	The beneficiary's HCC Risk Score, based on 2010 diagnoses.
HCC1	Num	HCC for HIV/AIDS
HCC2	Num	HCC for Septicemia/Shock
HCC5	Num	HCC for Opportunistic Infections
HCC7	Num	HCC for Metastatic Cancer and Acute Leukemia
HCC8	Num	HCC for Lung, Upper Digestive Tract, and Other Severe Cancers
HCC9	Num	HCC for Lymphatic, Head and Neck, Brain, and Other Major Cancers
HCC10	Num	HCC for Breast, Prostate, Colorectal and Other Cancers and Tumors
HCC15	Num	HCC for Diabetes with Renal or Peripheral Circulatory Manifestation
HCC16	Num	HCC for Diabetes with Neurologic or Other Specified Manifestation

**Table A-8: Frame Variables Used in Weighting (continued)**

Variable	Type	Description
HCC17	Num	HCC for Diabetes with Acute Complications
HCC18	Num	HCC for Diabetes with Ophthalmologic or Unspecified Manifestation
HCC19	Num	HCC for Diabetes without Complication
HCC21	Num	HCC for Protein-Calorie Malnutrition
HCC25	Num	HCC for End-Stage Liver Disease
HCC26	Num	HCC for Cirrhosis of Liver
HCC27	Num	HCC for Chronic Hepatitis
HCC31	Num	HCC for Intestinal Obstruction/Perforation
HCC32	Num	HCC for Pancreatic Disease
HCC33	Num	HCC for Inflammatory Bowel Disease
HCC37	Num	HCC for Bone/Joint/Muscle Infections/Necrosis
HCC38	Num	HCC for Rheumatoid Arthritis and Inflammatory Connective Tissue Disease
HCC44	Num	HCC for Severe Hematological Disorders
HCC45	Num	HCC for Disorders of Immunity
HCC51	Num	HCC for Drug/Alcohol Psychosis
HCC52	Num	HCC for Drug/Alcohol Dependence
HCC54	Num	HCC for Schizophrenia
HCC55	Num	HCC for Major Depressive, Bipolar, and Paranoid Disorders
HCC67	Num	HCC for Quadriplegia, Other Extensive Paralysis
HCC68	Num	HCC for Paraplegia
HCC69	Num	HCC for Spinal Cord Disorders/Injuries
HCC70	Num	HCC for Muscular Dystrophy
HCC71	Num	HCC for Polyneuropathy
HCC72	Num	HCC for Multiple Sclerosis
HCC73	Num	HCC for Parkinsons and Huntingtons Diseases
HCC74	Num	HCC for Seizure Disorders and Convulsions
HCC75	Num	HCC for Coma, Brain Compression/Anoxic Damage
HCC77	Num	HCC for Respirator Dependence/Tracheostomy Status
HCC78	Num	HCC for Respiratory Arrest
HCC79	Num	HCC for Cardio-Respiratory Failure and Shock
HCC80	Num	HCC for Congestive Heart Failure
HCC81	Num	HCC for Acute Myocardial Infarction
HCC82	Num	HCC for Unstable Angina and Other Acute Ischemic Heart Disease
HCC83	Num	HCC for Angina Pectoris/Old Myocardial Infarction
HCC92	Num	HCC for Specified Heart Arrhythmias
HCC95	Num	HCC for Cerebral Hemorrhage
HCC96	Num	HCC for Ischemic or Unspecified Stroke
HCC100	Num	HCC for Hemiplegia/Hemiparesis



**Table A-8: Frame Variables Used in Weighting (continued)**

Variable	Type	Description
HCC101	Num	HCC for Cerebral Palsy and Other Paralytic Syndromes
HCC104	Num	HCC for Vascular Disease with Complications
HCC105	Num	HCC for Vascular Disease
HCC107	Num	HCC for Cystic Fibrosis
HCC108	Num	HCC for Chronic Obstructive Pulmonary Disease
HCC111	Num	HCC for Aspiration and Specified Bacterial Pneumonias
HCC112	Num	HCC for Pneumococcal Pneumonia, Emphysema, Lung Abscess
HCC119	Num	HCC for Proliferative Diabetic Retinopathy and Vitreous Hemorrhage
HCC130	Num	HCC for Dialysis Status
HCC131	Num	HCC for Renal Failure
HCC132	Num	HCC for Nephritis
HCC148	Num	HCC for Decubitus Ulcer of Skin
HCC149	Num	HCC for Chronic Ulcer of Skin, Except Decubitus
HCC150	Num	HCC for Extensive Third-Degree Burns
HCC154	Num	HCC for Severe Head Injury
HCC155	Num	HCC for Major Head Injury
HCC157	Num	HCC for Vertebral Fractures without Spinal Cord Injury
HCC158	Num	HCC for Hip Fracture/Dislocation
HCC161	Num	HCC for Traumatic Amputation
HCC164	Num	HCC for Major Complications of Medical Care and Trauma
HCC174	Num	HCC for Major Organ Transplant Status
HCC176	Num	HCC for Artificial Openings for Feeding or Elimination
HCC177	Num	HCC for Amputation Status, Lower Limb/Amputation Complications

**Table A-9: Nonresponse Rates and Adjustment Factors for 10 Weighting Cells**

Weighting Cell	Cell Size	Respondent	Non-respondent	Unweighted Nonresp Rate	Weighted Nonresp Rate	Adjustment Factor
1	877	62	815	92.9%	92.8%	13.8450
2	877	144	733	83.6%	82.4%	5.6956
3	877	139	738	84.2%	85.3%	6.7962
4	878	180	698	79.5%	78.8%	4.7155
5	877	205	672	76.6%	76.7%	4.2895
6	877	239	638	72.7%	72.1%	3.5838
7	878	308	570	64.9%	65.8%	2.9270
8	877	353	524	59.7%	61.3%	2.5829
9	877	386	491	56.0%	55.6%	2.2502
10	878	519	359	40.9%	40.5%	1.6814
Total	8,773	2,535	6,238			

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## **APPENDIX B: BENEFICIARY SURVEY**

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Hello, my name is [INTERVIEWER NAME]. I'm calling on behalf of the Centers for Medicare and Medicaid Services the Medicare Agency. We're conducting a survey of people with kidney failure. You have been selected at random to be included in this important study.

Before we begin, there are a couple of important things I need to go over with you.

Your participation in this survey is voluntary. If you do not to participate, it will not affect your benefits in any way. The information you provide will be treated as confidential. We expect this interview to take approximately 15 minutes. If there is any question you would rather not answer, just tell me and I will skip it.

### **SCREENER - INTRODUCTION**

**1a. In the last 3 months have you received dialysis treatment?**

<sup>1</sup> ☐ YES

<sup>2</sup> ☐ NO [If NO, SKIP TO END]

<sup>-7</sup> ☐ REFUSED

<sup>-8</sup> ☐ DON'T KNOW

**1b. Have you had a kidney transplant since March of 2011?**

<sup>1</sup> ☐ YES [If YES, SKIP TO END]

<sup>2</sup> ☐ NO

<sup>-7</sup> ☐ REFUSED

<sup>-8</sup> ☐ DON'T KNOW

**These first questions are about the type of dialysis treatment you get.**

**2. Where do you currently get your dialysis treatments...**

**[IF NEEDED: If you get dialysis treatments in more than one setting, please tell us where you usually get dialysis treatments.] [INSTRUCTIONS TO INTERVIEWER: If respondent says it is owned by a hospital, but the dialysis center is not located physically within the hospital, it is still considered at a hospital]**

- <sup>1</sup> ☐ At home,
- <sup>2</sup> ☐ At a dialysis center, or
- <sup>3</sup> ☐ At a hospital?
- <sup>-7</sup> ☐ REFUSED – SKIP to Q4
- <sup>-8</sup> ☐ DON'T KNOW – SKIP to Q4

[PROGRAMMER, IF Q2=1, FILL DISPLAY WITH “home”; IF Q2=2 FILL DISPLAY WITH “a dialysis center”; IF Q2=3, FILL DISPLAY WITH “a hospital”.]

**3. How long have you been getting dialysis treatments at {home/a dialysis center/a hospital}? Would you say...**

- <sup>1</sup> ☐ Less than 3 months,
- <sup>2</sup> ☐ At least 3 months but less than 1 year,
- <sup>3</sup> ☐ At least 1 year but less than 5 years, or
- <sup>2</sup> ☐ 5 years or more?
- <sup>-7</sup> ☐ REFUSED
- <sup>-8</sup> ☐ DON'T KNOW

**4. What type of dialysis treatment do you currently get? Hemodialysis through the vein or peritoneal dialysis through the belly?**

- <sup>1</sup> ☐ HEMODIALYSIS
- <sup>2</sup> ☐ PERITONEAL DIALYSIS →Skip to 6
- <sup>-7</sup> ☐ REFUSED
- <sup>-8</sup> ☐ DON'T KNOW

5. The dialysis center staff can connect you to the dialysis machine through a graft, fistula, or catheter. In the last 3 months, which one did they use most often to connect you to the dialysis machine?

<sup>1</sup> ☐ GRAFT

<sup>2</sup> ☐ FISTULA

<sup>3</sup> ☐ CATHETER

<sup>-7</sup> ☐ REFUSED

<sup>-8</sup> ☐ DON'T KNOW

6. How many days per week do you usually get dialysis?

\_\_\_\_\_

7. How many hours do your dialysis treatments usually last?

\_\_\_\_\_

8. Now we are going to ask you about your kidney doctors. Your kidney doctors are the doctors most involved in your dialysis care. This could include kidney doctors that you see inside and outside of a clinic, hospital, or dialysis center. In the last 3 months, how often did your kidney doctors listen carefully to you? Would you say...

<sup>1</sup> ☐ Never,

<sup>2</sup> ☐ Sometimes,

<sup>3</sup> ☐ Usually, or

<sup>4</sup> ☐ Always?

<sup>-7</sup> ☐ REFUSED

<sup>-8</sup> ☐ DON'T KNOW

9. In the last 3 months, how often did your kidney doctors explain things in a way that was easy to understand? Would you say...

<sup>1</sup> ☐ Never,

<sup>2</sup> ☐ Sometimes,

<sup>3</sup> ☐ Usually, or

<sup>4</sup> ☐ Always?

<sup>-7</sup> ☐ REFUSED

<sup>-8</sup> ☐ DON'T KNOW

- 10. In the last 3 months, how often did your kidney doctors show respect for what you had to say?**
- <sup>1</sup> ☐ Never
  - <sup>2</sup> ☐ Sometimes
  - <sup>3</sup> ☐ Usually
  - <sup>4</sup> ☐ Always
  - <sup>-7</sup> ☐ REFUSED
  - <sup>-8</sup> ☐ DON'T KNOW
- 11. In the last 3 months, how often did your kidney doctors spend enough time with you?**
- <sup>1</sup> ☐ Never
  - <sup>2</sup> ☐ Sometimes
  - <sup>3</sup> ☐ Usually
  - <sup>4</sup> ☐ Always
  - <sup>-7</sup> ☐ REFUSED
  - <sup>-8</sup> ☐ DON'T KNOW
- 12. In the last 3 months, did you and your kidney doctors talk about starting or stopping a prescription medicine?**
- <sup>1</sup> ☐ YES
  - <sup>2</sup> ☐ NO → If NO, Go to Q16
  - <sup>-7</sup> ☐ REFUSED
  - <sup>-8</sup> ☐ DON'T KNOW
- 13. Did you and your kidney doctors talk about the reasons why you might want to take the prescription medicine?**
- <sup>1</sup> ☐ Yes
  - <sup>2</sup> ☐ No
  - <sup>-7</sup> ☐ REFUSED
  - <sup>-8</sup> ☐ DON'T KNOW

- 14. Did you and your kidney doctors talk about the reasons why you might not want to take the prescription medicine?**
- <sup>1</sup> ☐ Yes
- <sup>2</sup> ☐ No
- <sup>-7</sup> ☐ REFUSED
- <sup>-8</sup> ☐ DON'T KNOW
- 15. When you talked about starting or stopping a prescription medicine, did your kidney doctors ask what you thought was best for you?**
- <sup>1</sup> ☐ YES
- <sup>2</sup> ☐ NO
- <sup>-7</sup> ☐ REFUSED
- <sup>-8</sup> ☐ DON'T KNOW
- 16. Using any number from 0 to 10, where 0 is the worst kidney doctors possible and 10 is the best kidney doctors possible, what number would you use to rate the kidney doctors you have now?**
- 0 Worst kidney doctors possible
- 1
- 2
- 3
- 4
- 5
- 6
- 7
- 8
- 9
- 10 Best kidney doctors possible

[PROGRAMMER, FILL Q17 IF Q2=1 (HOME DIALYSIS), DO NOT SHOW DISPLAY; IF Q2=2 (DIALYSIS AT A CENTER) FILL DISPLAY WITH "dialysis center"; IF Q2=3 (DIALYSIS AT A HOSPITAL), FILL DISPLAY WITH "hospital dialysis center".]



- 17. Now we are going to ask you to think about all the people on your kidney care team. This includes nurses, technicians, social workers, and dieticians at the [PROGRAMMER PLEASE INCLUDE DISPLAY FOR -- dialysis center, / hospital dialysis center]. In the last 3 months, how often did your kidney care team treat you with courtesy and respect? Would you say...**

- <sup>1</sup> ☐ Never,  
<sup>2</sup> ☐ Sometimes,  
<sup>3</sup> ☐ Usually, or  
<sup>4</sup> ☐ Always?  
<sup>-7</sup> ☐ REFUSED  
<sup>-8</sup> ☐ DON'T KNOW

**PROGRAMMER BOX 2:**

IF Q2=1 (CURRENTLY GETTING DIALYSIS TREATMENT AT HOME) SKIP TO #21  
ELSE, GO TO #18.

- 18. In the last 3 months, how often did your kidney care team spend enough time with you? Would you say...**

- <sup>1</sup> ☐ Never,  
<sup>2</sup> ☐ Sometimes,  
<sup>3</sup> ☐ Usually, or  
<sup>4</sup> ☐ Always?  
<sup>-7</sup> ☐ REFUSED  
<sup>-8</sup> ☐ DON'T KNOW

- 19. In the last 3 months, how often did your kidney care team make you as comfortable as possible during dialysis?**

- <sup>1</sup> ☐ Never  
<sup>2</sup> ☐ Sometimes  
<sup>3</sup> ☐ Usually  
<sup>4</sup> ☐ Always  
<sup>-7</sup> ☐ REFUSED  
<sup>-8</sup> ☐ DON'T KNOW

**20. In the last 3 months, how often did your kidney care team check you as closely as you wanted while you were on the dialysis machine?**

- <sup>1</sup> ☐ Never
- <sup>2</sup> ☐ Sometimes
- <sup>3</sup> ☐ Usually
- <sup>4</sup> ☐ Always
- <sup>-7</sup> ☐ REFUSED
- <sup>-8</sup> ☐ DON'T KNOW

**21. Using any number from 0 to 10, where 0 is the worst kidney care team possible and 10 is the best kidney care team possible, what number would you use to rate your kidney care team?**

0 Worst kidney care team possible

- 1
- 2
- 3
- 4
- 5
- 6
- 7
- 8
- 9

10 Best kidney care team possible

**22. Are you eligible for a kidney transplant?**

- <sup>1</sup> ☐ YES → If YES, Go to Q25
- <sup>2</sup> ☐ NO
- <sup>-7</sup> ☐ REFUSED
- <sup>-8</sup> ☐ DON'T KNOW

**23. For this question, think about the last 12 months. In the last 12 months, did your kidney doctors or anyone on your kidney care team explain why you are not eligible for a kidney transplant?**

- <sup>1</sup> ☐ YES
- <sup>2</sup> ☐ NO
- <sup>-7</sup> ☐ REFUSED
- <sup>-8</sup> ☐ DON'T KNOW

- 24. For this question, think about the last 12 months. In the last 12 months, did your kidney doctors or anyone on your kidney care team talk with you as much as you wanted about a kidney transplant?**

<sup>1</sup> ☐ YES  
<sup>2</sup> ☐ NO  
<sup>-7</sup> ☐ REFUSED  
<sup>-8</sup> ☐ DON'T KNOW

IF Q4=2 (CURRENTLY GETTING PERITONEAL DIALYSIS TREATMENT) SKIP TO #26  
ELSE, GO TO #25.

- 25. For this question, think about the last 12 months. Peritoneal dialysis is dialysis given through the belly and is usually done at home. In the last 12 months, did your kidney doctors or anyone on your kidney care team talk with you as much as you wanted about peritoneal dialysis?**

<sup>1</sup> ☐ YES  
<sup>2</sup> ☐ NO  
<sup>-7</sup> ☐ REFUSED  
<sup>-8</sup> ☐ DON'T KNOW

- 26. For the next questions, think about the last 3 months. In the last 3 months, did your kidney doctors or anyone on your kidney care team talk to you about what you should eat and drink?**

<sup>1</sup> ☐ YES  
<sup>2</sup> ☐ NO  
<sup>-7</sup> ☐ REFUSED  
<sup>-8</sup> ☐ DON'T KNOW

- 27. In the last 3 months, did your kidney doctors or anyone on your kidney care team work with you to set specific goals for managing your health?**

<sup>1</sup> ☐ YES  
<sup>2</sup> ☐ NO → If NO go to Q29  
<sup>-7</sup> ☐ REFUSED  
<sup>-8</sup> ☐ DON'T KNOW

**28. In the last 3 months, did your kidney doctors or anyone on your kidney care team offer you help to reach these goals?**

<sup>1</sup> ☐ YES

<sup>2</sup> ☐ NO

<sup>-7</sup> ☐ REFUSED

<sup>-8</sup> ☐ DON'T KNOW

**29. In the last 3 months, did your kidney doctors or anyone on your kidney care team ask you about your mental or emotional health?**

<sup>1</sup> ☐ YES

<sup>2</sup> ☐ NO

<sup>-7</sup> ☐ REFUSED

<sup>-8</sup> ☐ DON'T KNOW

**30. In the last 3 months, did your kidney doctors or anyone on your kidney care team ask you about how your kidney disease affects other parts of your life?**

<sup>1</sup> ☐ YES

<sup>2</sup> ☐ NO

<sup>-7</sup> ☐ REFUSED

<sup>-8</sup> ☐ DON'T KNOW

**Now we are going to ask you about how much your health affects other parts of your life and daily activities. Some people are bothered by the effects of kidney disease on their daily life, while others are not. How much does kidney disease bother you in each of the following areas?**

**31. In the last 3 months, how often have you been bothered by fluid restrictions?  
Would you say...**

<sup>1</sup> ☐ Never,

<sup>2</sup> ☐ Sometimes,

<sup>3</sup> ☐ Usually, or

<sup>4</sup> ☐ Always?

<sup>-7</sup> ☐ REFUSED

<sup>-8</sup> ☐ DON'T KNOW

**32. In the last 3 months, how often have you been bothered by dietary restrictions?  
Would you say...**

- <sup>1</sup> ☐ Never,  
<sup>2</sup> ☐ Sometimes,  
<sup>3</sup> ☐ Usually, or  
<sup>4</sup> ☐ Always?  
<sup>-7</sup> ☐ REFUSED  
<sup>-8</sup> ☐ DON'T KNOW

**33. In the last 3 months how often have you felt downhearted and blue?**

- <sup>1</sup> ☐ Never  
<sup>2</sup> ☐ Sometimes  
<sup>3</sup> ☐ Usually  
<sup>4</sup> ☐ Always  
<sup>-7</sup> ☐ REFUSED  
<sup>-8</sup> ☐ DON'T KNOW

**34. In the last 3 months, how many days total did you stay in any hospital overnight?**

\_\_\_\_\_ days

**35. Excluding scheduled treatments, tests, or dialysis, in the last 3 months, how many days total did you receive care at a hospital, but came home the same day?**

\_\_\_\_\_ days

**36. In the last 3 months how many dialysis related infections did you have?**

\_\_\_\_\_ infections

**37. In general, how would you rate your overall physical health? Would you say...**

- <sup>1</sup> ☐ Excellent,
- <sup>2</sup> ☐ Very good,
- <sup>3</sup> ☐ Good,
- <sup>4</sup> ☐ Fair, or
- <sup>5</sup> ☐ Poor?
- <sup>-7</sup> ☐ REFUSED
- <sup>-8</sup> ☐ DON'T KNOW

**38. In general, how would you rate your overall mental or emotional health? Would you say...**

- <sup>1</sup> ☐ Excellent,
- <sup>2</sup> ☐ Very good,
- <sup>3</sup> ☐ Good,
- <sup>4</sup> ☐ Fair, or
- <sup>5</sup> ☐ Poor?
- <sup>-7</sup> ☐ REFUSED
- <sup>-8</sup> ☐ DON'T KNOW

**Now we are going to ask you about the insurance you may have and the cost of your dialysis treatment.**

**39. Some people who are eligible for Medicare or Medicaid also have another type of insurance. Do you have any of the following types of health insurance... [YES/NO/REFUSED/DON'T KNOW TO EACH]**

- <sup>1</sup> ☐ Medigap or Medicare Supplement?
- <sup>2</sup> ☐ Medicare Special Needs Plan?
- <sup>3</sup> ☐ Medicare Advantage?
- <sup>4</sup> ☐ Insurance through your or your spouse's employer or former employer?
- <sup>5</sup> ☐ Insurance through the VA?
- <sup>6</sup> ☐ Insurance that you purchased directly?
- <sup>7</sup> ☐ Any other type of health insurance?

**40. Are you covered for your prescription drugs through any of the following health plans?**

[YES/NO/REFUSED/DON'T KNOW TO EACH]

<sup>1</sup> ☐ Medicare Part D [IF NEEDED: The Medicare prescription drug plan]?

<sup>2</sup> ☐ Medicaid?

<sup>3</sup> ☐ Low Income Subsidy?

<sup>4</sup> ☐ A private prescription drug plan or any other kind of plan?

**41. In the last 3 months, were you ever worried or concerned about the cost of your dialysis treatments, tests, or prescription medicines?**

<sup>1</sup> ☐ YES

<sup>2</sup> ☐ NO

<sup>-7</sup> ☐ REFUSED

<sup>-8</sup> ☐ DON'T KNOW

**42. In the last 3 months, did you and your kidney doctors or anyone on your kidney care team talk about the cost of your dialysis treatments, tests, or prescription medicines?**

<sup>1</sup> ☐ YES

<sup>2</sup> ☐ NO

<sup>-7</sup> ☐ REFUSED

<sup>-8</sup> ☐ DON'T KNOW

**43. In the last 3 months, did you delay or not get dialysis treatments, tests, or medicines prescribed for you?**

<sup>1</sup> ☐ YES

<sup>2</sup> ☐ NO → If NO, Go to Q45

<sup>-7</sup> ☐ REFUSED

<sup>-8</sup> ☐ DON'T KNOW

**44. Was cost or lack of insurance a reason why you delayed getting dialysis treatments, tests, or prescription medicines?**

<sup>1</sup> ☐ YES

<sup>2</sup> ☐ NO

<sup>-7</sup> ☐ REFUSED

<sup>-8</sup> ☐ DON'T KNOW

**The last few questions are about you.**

**45. Are you of Hispanic or Latino origin or descent?**

- <sup>1</sup> ☐ YES, HISPANIC OR LATINO
- <sup>2</sup> ☐ NO, NOT HISPANIC OR LATINO
- <sup>-7</sup> ☐ REFUSED
- <sup>-8</sup> ☐ DON'T KNOW

**46. Please tell me which one or more of the following you would use to describe yourself. Would you describe yourself as...**

- <sup>1</sup> ☐ Native Hawaiian or Other Pacific Islander,
- <sup>2</sup> ☐ American Indian or Alaska Native,
- <sup>3</sup> ☐ Asian,
- <sup>4</sup> ☐ Black or African American, or
- <sup>5</sup> ☐ White?
- <sup>-7</sup> ☐ REFUSED
- <sup>-8</sup> ☐ DON'T KNOW

**47. What is the highest grade or level of school that you have completed?**

- <sup>1</sup> ☐ 8TH GRADE OR LESS
- <sup>2</sup> ☐ SOME HIGH SCHOOL, BUT DID NOT GRADUATE
- <sup>3</sup> ☐ HIGH SCHOOL GRADUATE OR GED
- <sup>4</sup> ☐ SOME COLLEGE OR 2-YEAR DEGREE
- <sup>5</sup> ☐ 4-YEAR COLLEGE GRADUATE
- <sup>6</sup> ☐ MORE THAN 4-YEAR COLLEGE DEGREE
- <sup>-7</sup> ☐ REFUSED
- <sup>-8</sup> ☐ DON'T KNOW



**48. Are you now...**

- <sup>1</sup> ☐ married,
- <sup>2</sup> ☐ living with a partner in a marriage-like relationship,
- <sup>3</sup> ☐ widowed,
- <sup>4</sup> ☐ divorced,
- <sup>5</sup> ☐ separated, or
- <sup>6</sup> ☐ never married?
- <sup>-7</sup> ☐ REFUSED
- <sup>-8</sup> ☐ DON'T KNOW

**49. What was your household annual income from all sources before taxes?**

- <sup>1</sup> ☐ Less than \$10,000
- <sup>2</sup> ☐ \$10,001 to \$20,000
- <sup>3</sup> ☐ \$20,001 to \$30,000
- <sup>4</sup> ☐ \$30,001 to \$40,000
- <sup>5</sup> ☐ \$40,001 to \$50,000
- <sup>6</sup> ☐ \$50,001 to \$60,000
- <sup>7</sup> ☐ \$60,001 to \$70,000
- <sup>8</sup> ☐ \$70,001 to \$80,000
- <sup>9</sup> ☐ \$80,001 to \$90,000
- <sup>10</sup> ☐ \$90,001 to \$100,000
- <sup>11</sup> ☐ \$100,001 or more
- <sup>-7</sup> ☐ REFUSED
- <sup>-8</sup> ☐ DON'T KNOW

**50. Including yourself, how many people living in your household are supported by your total household income?**

\_\_\_\_\_ NUMBER OF PEOPLE {Range 1-20}

[PROGRAMMER NOTE: Only show open-ended questions for 30 respondents]

Now we are going to ask you to comment on a few areas of your dialysis care.

OP1. Please describe your experience with getting your kidney care over the last three months.  
[PROGRAMMER NOTE, ASK OF FLAGGED OPEN ENDED CASES ONLY]

OP2. Thinking about your experience with your kidney doctors and your kidney care team, please describe the care you received over the last three months. [PROGRAMMER NOTE, ASK OF FLAGGED OPEN ENDED CASES ONLY]

OP3. Please describe how your kidney care treatment has affected your overall health? [PROGRAMMER NOTE, ASK OF FLAGGED OPEN ENDED CASES ONLY]

OP4. How have you been impacted by the cost of your kidney care? [PROGRAMMER NOTE, ASK OF FLAGGED OPEN ENDED CASES ONLY]

THANK YOU FOR TAKING THE TIME TO ANSWER THE END STAGE RENAL MEDICARE BENEFICIARY SURVEY. IF YOU HAVE ANY QUESTIONS, PLEASE DO NOT HESITATE TO CONTACT US AT [     ].

THANK YOU.

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## APPENDIX C: BENEFICIARY SURVEY PRENOTIFICATION LETTER

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DEPARTMENT OF HEALTH & HUMAN SERVICES  
Centers for Medicare & Medicaid Services  
7500 Security Boulevard, Mail Stop S2-24-25  
Baltimore, Maryland 21244-1850

CMS Privacy Office

[NAME]  
[ADDRESS 1]  
[ADDRESS 2]  
[CITY], [STATE] [ZIP]

Dear [NAME]:

I'm writing to ask you to take part in an important national survey about people with End Stage Renal Disease (ESRD). The Centers for Medicare and Medicaid Services, the agency that runs Medicare, is gathering information about your experiences in getting health care. We want to make sure that you are getting the best possible care so we need to hear about your experiences.

- It should take less than a half hour to participate in the survey.
- Participation in the survey is voluntary and will not affect your Medicare benefits.
- Through the survey we hope to learn how to improve care for beneficiaries with ESRD.
- A telephone interviewer will call you to complete the survey.

Your name was chosen from among all beneficiaries with ESRD. It is very important that we talk to everyone selected to participate. Your answers to the survey questions will be treated as confidential.

To help us in conducting the survey a telephone interviewer from Westat will call you in the next week to conduct the survey interview. If we are unable to reach you, please let us know when we can call you back. We appreciate your taking the time to participate in our survey.

Thank you in advance for your cooperation. If you have any questions about the survey, please call 1-888-960-1283 or send an email to [ESRDSurvey@westat.com](mailto:ESRDSurvey@westat.com).

Sincerely,

Walter Stone  
Privacy Officer

## APPENDIX D: STAKEHOLDER INTERVIEW PROTOCOL

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The Centers for Medicare & Medicaid Services (CMS) has implemented revisions to its reimbursement system for ESRD services. These changes are being rolled out in stages; the ESRD Prospective Payment System (PPS) began in January 2011, and the Quality Incentive Program (QIP) will begin in January 2012. The new system entails bundled reimbursements that are linked to performance measures and beneficiary outcomes.

This interview will focus on how the ESRD PPS/ QIP has affected beneficiary care, for example, beneficiary experience of and satisfaction with care; beneficiary quality of life; quality of dialysis; intended versus unintended consequences for beneficiary care; changes in beneficiary access to care; and beneficiary safety issues.

**Purpose:** The information gathered in this interview will help CMS in understanding the effects of the ESRD PPS/QIP.

**Sponsorship:** Westat is a subcontractor to Acumen who is conducting this project on behalf of CMS.

**What is involved:** We will be asking you to discuss various topics related to the ESRD PPS/QIP. Sometimes, we will ask you to say more about certain topics or for clarification or examples.

**Voluntary:** Your participation in this research project is voluntary, and you have the right to stop at any time or to refuse to answer any question. The session will take approximately 60 minutes.

**Recording:** We would like to record the interview. Sometimes it is helpful to review the recording as we develop our notes. If the recording is reviewed later, it will only be by a few Westat staff. The recordings will be destroyed within six weeks of the end of the study.

**Confidentiality:** You will never be identified by name. The things you say may be put in a written summary of this discussion, but there will be no way to identify who said what, and your name will not be used anywhere.

**Risks:** The only cost to you is the time and effort to participate in this interview.

**Benefits:** There are no direct benefits to you for participating in this study. However, you will be helping with an important research project.

**Questions:** If you have questions about the project, you may call the Project Director, Stephanie Fry at 301-294-2872. For questions about your rights and welfare as human subjects in this study, you may call the Institutional Review Board at Westat at 301-610-8828.

**1. Provider/Expert Understanding of and Experience with ESRD PPS/QIP**

a. Could you tell us about your organization?

Probe:

- Non-profit/for-profit; urban/rural, suburban, geographic area, high/low volume organization, etc. What does the organization do?
- How does your job bring you into contact with ESRD beneficiaries?

b. Could you tell us in your own words what the ESRD PPS/QIP is all about?

Probe:

- Could you provide some examples?

**2. Effects and Implications of the ESRD PPS/QIP Changes**

**Access to Care**

- Can you say something about the factors that determine access to care for beneficiaries?
- Have any disparities in access to care emerged or has access to care remained the same?
- How about vulnerable populations: minorities, elderly, rural, noninsured, undocumented, mental health comorbidities, home hemodialysis beneficiaries?
- Have any beneficiaries not been accepted under the new system who would have been accepted under the previous system?

Can you say more about that?

**Access to Care Checklist**

- Any cherry-picking among beneficiaries
- Increase or decrease in voluntary discharges due to lack of adherence
- Any facility closure without alternatives for beneficiaries

Can you say more about that?

**Cost of Care**

- Can you talk about the cost of care to beneficiaries under the ESRD PPS/QIP?
- Can you talk about the cost of care to providers under the ESRD PPS/QIP?

Can you say more about that?

**Cost of Care Checklist**

- Shift of costs through copays/self-pay for therapies, supplies, drugs, etc.
- Shift of costs to other care setting: hospital ER; dual-eligible state Medicaid, other agencies?

### **3. Drugs and Biologicals**

- a. Have beneficiaries at your facility/organization experienced any of the following as a consequence of the implementation of ESRD PPS/QIP?
  - Formulary and protocol changes;
  - Use of oral drugs vs. injectable equivalents (iron, vitamin D)
  - Changes in the use of erythropoiesis stimulating agents (ESA) – costs, therapeutic options, administration mode, dosing intervals, etc.;
  - Use of antibiotic therapies (e.g. daptomycin, vancomycin) for ESRD-related infections;
  - Treatment of bone and mineral disorders;
  - Implications of other drug coverage (e.g. Part D) and confusion of what drugs are included;
  - Availability of mail order options for beneficiaries;
  - Availability of pharmacy services in small organizations; and
  - Any adverse events related to medication incentive changes.

Can you say more about that?

### **4. Laboratory Tests**

- a. Since the implementation of ESRD PPS/QIP, have you seen a reduction or increase in the frequency with which laboratory tests have been prescribed for beneficiaries?
- b. Since the implementation of ESRD PPS/QIP, have you seen that the responsibility for ESRD laboratory tests has shifted to other providers (e.g. primary care physicians)?
- c. Since the implementation of ESRD PPS/QIP, have ESRD related tests, for example, transplant evaluation, not been included in the serviced provided to beneficiaries?
- d. Has the coordination of lab results for beneficiaries been achieved among providers and labs since the implementation of ESRD PPS/QIP?
- e. Has the implementation of ESRD PPS/QIP affected the tracking or billing of lab tests?

Can you say more about that?

### **5. Quality of Care Measure and Health Outcomes**

- a. Can you say something about how ESRD PPS/QIP have affected health outcomes for beneficiaries?
  - Hospitalization rates;
  - Anemia management, blood transfusion rates;
  - Dialysis adequacy;
  - Levels of phosphorous, calcium, parathyroid hormone;
  - Beneficiary safety issues, including under-treatment;
  - Use of evidence-based protocols, plans of care;
  - Infection rates, including vascular access; and
  - Complication rates of dialysis.

**6. Beneficiary Choice and Education**

- a. How easy or difficult has it been for beneficiaries to understanding the changes?
- b. Has the information/education provided to beneficiaries regarding treatment options other than in-center dialysis changed since ESRD PPS started? [IF YES] Can you say more about that?
- c. Are there mechanisms in your organization that allow beneficiaries to share in the decision-making for different treatment options?
- d. How much choice do beneficiaries have regarding treatments and medicines under the ESRD PPS/QIP?
- e. What type of impact you think that ESRD PPS/QIP has had on patient education (e.g., self-management activities, fluid, nutrition, medications, vascular, access, drugs, and so forth)?

[POSITIVE IMPACT TO IMPROVE COMPLIANCE AND QIP SCORE OR NEGATIVE IMPACT BECAUSE OF COMPETING PRIORITIES FOR FACILITY PERSONNEL]

Can you say more about that?

**7. Consumer Satisfaction/Experience of Care**

- a. Has the ESRD PPS/QIP changed any of the following for the beneficiaries:
  - Perceptions that the facility is adequately staffed;
  - Increase in cost to the beneficiary;
  - Inconvenience (e.g. lab tests at multiple places), less beneficiary-centered;
  - Increased or decreased quality of life; and
  - Health outcomes (increase in hospitalizations, ER visits, infections).

Can you say more about that?

**8. Supplies, Devices and Durable Medical Equipment**

- a. Since implementation, have you seen that lower cost supplies or less expensive devices have been substituted?
- b. Since implementation, have you seen that fewer supplies have been available for beneficiaries?
- c. Since implementation, have you seen that fewer beneficiary choices are available to beneficiaries and that supply costs have been shifted to the beneficiaries?
- d. Since the implementation, have you seen any difference in beneficiaries' ability to obtain necessary items cost-effectively outside a group purchasing organization?

Can you say more about that?



## **9. Implementation Issues**

- a. Has implementation changed the way organization/facilities:
  - Bill or process claims?
  - Staff the dialysis facilities?
- b. Have the changes been implemented in a uniform way or have different beneficiaries had different experiences of implementation?

## **10. ICH-CAHPS Survey**

- a. How familiar are you with the current ICH-CAHPS survey? [The In-Center Hemodialysis CAHPS Survey asks adults with ESRD about their experiences with the facility that provides their hemodialysis.]
- b. Do you use the findings from this survey or use the survey questions to improve the experience of care by patients?
- c. The ICH-CAHPS survey covers patient experience measures related to:
  - Nephrologist's Communication and Caring
  - Quality of Dialysis Center Care and Operations
  - Dialysis Center Staff Providing Information to Patients
- d. As a measure of patient experience with in-center hemodialysis, what other topics should be covered?
- e. Thinking about the implementation of ESRD PPS/QIP, what other domains or topics could be included in the ICH-CAHPS survey to measure beneficiary experience of care? Examples include transitions of care, care coordination among providers, beneficiary knowledge of local resources, benefits, eligibility for assistance, beneficiary rights, beneficiary safety issues, beneficiary self-management? Or perhaps facility issues, such as opening on time, waiting room for family, staff professionalism? Another area could be the need for additional surveys relevant to home dialysis or peritoneal and surveys translated into other languages.
- f. Other topics?
- g. Do you see the ICH-CAHPS data used in presentations or articles?
- h. How useful would you say the current ICH-CAHPS survey is?
- i. Has your organization seen or used other survey instruments that were useful? Can you say more about that?

## **11. Closing**

- a. Do you have any other comments about the effects on beneficiaries that the ESRD PPS/QIP has had?

## APPENDIX E: REFERENCES

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